"WHY HAVE I HAD TO FIGHT THIS HARD?" EXPERIENCES OF ABORIGINAL CAREGIVERS WHO HAVE CHILDREN DIAGNOSED WITH ADHD

by

Nicole Sawin

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Abstract

Attention-deficit/hyperactivity disorder (ADHD) is a controversial diagnosis that is debated in public and professional spheres. However, the experiences of Aboriginal peoples have largely not been included in this debate. Considering that reactions to trauma may include hyperactivity and attention-deficits, and that mental health is defined differently in different cultures, this is arguably problematic. This research uses a qualitative exploratory approach embedded in an anti-oppressive social work research framework to explore the experiences of four urban Aboriginal mothers of children diagnosed with ADHD in Northern British Columbia. It was found that Aboriginal caregivers experience many challenges already recorded in the literature, and that they also grapple with the impacts of colonialism and intergenerational trauma in different ways. When considering the principles of allyship and anti-oppressive practice, this raises ethical questions about where the burden of responsibility lies, as well as how ADHD is currently defined and used in practice.

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Acknowledgement

I would like to take this opportunity to acknowledge the participants in this research, my supervisor, my supervisory committee, my advisory committee, and other key people without which this study would not have been completed. First, I would like to express deep and heartfelt gratitude to the caregivers who shared their stories with me. Your courage and vulnerability are inspiring. Second, I would like to thank my supervisor Glen for being an incredible support, always willing to answer an email no matter the time of day. Third, I would like to express gratitude to my supervisory committee, Linda and Susan, whose compassion and kindness helped give me courage. Fourth, a heartfelt thank you to my advisory committee who took the time to give me feedback even when a global pandemic had turned all our lives upside down. Finally, there are several people without which this study would not have occurred: Erin at the Native Friendship Center who was willing to meet with me in its early stages; Trish at School District 57 who helped me reach more caregivers; and my supervisor at Intersect Youth and Family Services, Melissa, who helped me manage my school-work balance and was always ready with encouraging words.

Dedication

I dedicate this thesis to the young boy and his mother who inspired it.

Chapter One: Introduction

Jordan[1] is a young Aboriginal boy I worked with as a child and youth mental health counsellor. His school called him "unmanageable," "angry and resentful," and a "bully," and his pediatrician diagnosed him with attention-deficit/hyperactivity disorder (ADHD) and prescribed him stimulant medications. However, I was honoured to be invited into a deeper understanding of his story and the story of his family. It was a story fraught with intergenerational, historic, and ongoing trauma and loss and, with it, I developed a different perspective than his school or pediatrician. Where they saw problem behavior and a medical diagnosis, I saw a young boy doing an amazing job surviving using the skills he had developed to keep himself safe when he was growing up. In other words, I saw incredible strength.

With my background in sociology, I have always been interested in the social construction of mental illness and I already knew that ADHD is a particularly controversial diagnosis. However, Jordan opened my eyes to how the sociological concepts I learned during my undergraduate studies can impact marginalized populations in practice. As such, I became extremely interested in ADHD, started reading, and found that very few studies had explored the experiences of Aboriginal peoples and their families diagnosed with ADHD like Jordan. This is despite the fact that the Aboriginal Peoples Survey found that off-reserve First Nations boys (13%) and girls (5%) are more likely to be diagnosed with ADHD than non-Aboriginal boys (2%) and girls (1%) (Statistics Canada, 2006), and research has consistently found higher rates of ADHD among Indigenous populations than the general population (Baydala et al., 2006).

There are two issues to consider when applying an ADHD diagnosis to an Aboriginal child. First, Aboriginal peoples in Canada have experienced extensive colonial violence that is

[1] A pseudonym to protect the identity of this young person.

ongoing to this day and their communities continue to suffer from intergenerational trauma. Research suggests that reactions to trauma may include attention deficits and impulsive behaviors (Becker-Blease & Freyd, 2008; Cromer & Villodas, 2017; Ford et al., 2000) and has found that children exposed to adverse childhood experiences are more likely to be diagnosed with ADHD (Baglivio et al., 2017; Bethell et al., 2014; Çoban & Tan, 2020; Fuller-Thomson et al., 2014; Hunt et al., 2017; Schilpzand et al., 2018). Therefore, there has been speculation by psychiatrists, pediatricians, practitioners, and others in the academic community that behaviors which developed as a way to cope with such trauma may be misdiagnosed as ADHD (Bith-Melander et al., in press; Isaacs, 2006; Klein et al., 2015; Koprowski, 2015).

Second, mental health is defined differently according to the traditional knowledge of many Aboriginal peoples (Vukic et al., 2011), knowledge which has been marginalized by colonialism. Psychiatric and mental health services, largely grounded in a Western paradigm, have long played a role in the colonial violence against Aboriginal peoples. In a study on life stories from a federal psychiatric hospital for Native Americans in the United States, Burch (2016) argues that medical diagnoses were used to disrupt kinship relations, dominate Native Americans, and pathologize behavior norms in their culture. In Canada, Linklater (2014) cautions against the use of Western psychiatry with Aboriginal peoples because of the role it played in colonialism and gives examples of families being separated based on psychiatric labels and justifications. Indeed, British psychiatrist Sami Timimi (2014) has challenged the use of psychiatric diagnoses in general, arguing that they impose Western beliefs on other cultures. Moreover, psychiatric diagnoses have been argued to obscure issues such as racialized discrimination and poverty (Allan & Harwood, 2016).

Therefore, the purpose of my research was to explore Aboriginal perspectives of ADHD among caregivers of children diagnosed with it. My research question was as follows: What are the experiences of Aboriginal peoples in Northern BC acting as caregivers to Aboriginal children diagnosed with ADHD?

Personal Location: Cultural Humility

Social work has long been dominated by cultural competence models (Sue et al., 1982; Yan & Wong, 2005). However, cultural competence has been criticized for failing to account for health, economic, and social inequalities connected to long-standing oppression; for using "culture" as a proxy for non-white racial identities; for treating culture as static; for presenting "culture" as something that is monolithic and knowable, leading to the perpetuation of stereotypes; and for neglecting values of social justice (Fisher-Borne et al., 2015). Instead, cultural humility has been proposed as an alternative (Fisher-Borne et al., 2015) and has been discussed in the context of child welfare (Ortega & Coulborn, 2011) and social work graduate education (Rosen et al., 2017). Cultural humility is the concept that I will use in this study.

Cultural humility was first described by Tervalon and Murray-Garcia (1998) as including elements such as lifelong self-reflection, the mitigation of power imbalances, and institutional and individual accountability. Yeager and Bauer-Wu (2013) define cultural humility as a "lifelong process of self-reflection and self-critique whereby the individual not only learns about another's culture, but one starts with an examination of her/his own beliefs and cultural identities" (p. 251-252). It places professionals in a position of learning rather than one in which they hold power, control, and authority over knowledge that their clients undoubtedly know much more about (Ortega & Coulborn, 2011). Cultural humility has three components: (a) reflection, (b) institutional and individual accountability, and (c) the mitigation of systemic

power imbalances (Fisher-Borne et al., 2015). This examination of personal beliefs and cultural identity arguably makes cultural humility consistent with reflexivity, a concept which has been defined as a stance in which researchers reflect on their own background, culture, and experiences in order to explore how it may influence the research (Creswell, 2014; Fook, 2016). This is different from reflection which involves a process of thinking about practice without exploring the impact of your own personal location (Fook, 2016). Reflexivity has been identified as an important element in good qualitative research (Creswell & Poth, 2018; Tracy, 2010); has been connected with benefits such as greater integrity of the research process, better quality of knowledge generated, increased ethical treatment of participants, and personal growth of the researcher (Probst, 2015); and has been highlighted as being especially important in cross-cultural contexts (Caretta, 2014).

As suggested by Yeager and Bauer-Wu (2013), I will start with an initial examination of my own beliefs and cultural identities. I am a nonbinary individual, assigned female at birth, of mixed eastern European and British Isles descent who is third generation Canadian. I want to acknowledge that I grew up as an uninvited guest on Treaty 8 territory in Thecannie Kóe. My hometown is called Fort Nelson and is located in Northern British Columbia, about 10 hours north of Prince George. I completed an undergraduate degree in Honors Sociology at McGill University in Montreal, Quebec.

There are four elements in my personal location which influence me in relation to this research. First, when I was an adolescent, I was diagnosed with a mental illness. This mental illness has arguably generated as much global debate as ADHD. Being from a rural northern town and having received treatment in an urban center, I experienced how the biomedical approach to treatment can pathologize people who do not fit the dominant culture. This creates a

personal connection for me to the idea that the ADHD diagnosis may impose Western beliefs on other cultures.

Second, I worked as a research assistant for three years under Dr. Myriam Denov at McGill University in international social work. Dr. Denov values participatory approaches and views research as a tool of empowerment for marginalized peoples. Her approach to research profoundly impacted my own views toward research as being a means of achieving social justice. Therefore, I must be particularly aware that research has historically been a tool of colonial violence against Aboriginal peoples.

Third, I initially wanted to become a pediatrician and began my undergraduate degree in the sciences. However, I quickly learned that I did not like the biomedical approach to social problems because it seemed to be missing too many factors in peoples' lives. Therefore, I completed a Bachelor of Arts in Honors Sociology instead. I also worked as a research assistant for Dr. Bobby Das, a researcher exploring how biological, psychological, and social factors interact to produce and influence outcomes. Therefore, I do not believe in simple explanations for mental illnesses and problems with mental health, which makes me skeptical of explanations of ADHD which rely solely on medical, cultural, or social factors.

Finally, I work as a child and youth mental health counsellor using evidence-based approaches to support children and youth struggling with their mental health. In my position, I have seen how the dominant discourse is not always the best fit for many Aboriginal families, as illustrated by the case of Jordan in the introduction.

In sum, my background and experience both biases me against the biomedical framework and inclines me toward more complex and multifaceted explanations of mental illnesses and mental health problems. It was important for me to remain reflexive throughout the research to

explore how my personal location influenced it, as well as to practice cultural humility to open myself to learning about participants' experiences. To do this, I kept a research journal. As suggested by Yeager and Bauer-Wu (2013), I examined my own personal values, beliefs, and biases derived from my own culture; and I reflected on my profession and the values, beliefs, and biases derived from it as a cultural system. Fisher-Borne et al. (2015) also suggest several questions for critical self-reflection, as well as questions to address power imbalances at the individual and at the institutional level. I journaled on the questions suggested at the individual level before entering the field to set a foundation for my practice of cultural humility in this study. These questions were as follows:

- Questions for critical self-reflection include: What are my cultural identities? How do my cultural identities shape my worldview? How does my own background help or hinder my connection to clients/communities? What are my initial reactions to clients, specifically those who are culturally different from me? How much do I value input from my clients? How do I make space in my practice for clients to name their own identities? What do I learn about myself through listening to clients who are different than me? (Fisher-Borne et al., 2015)
- Questions to address power imbalances include: What social and economic barriers impact a client's ability to receive effective care? What specific experiences are my clients having that are related to oppression and/or larger systemic issues? How do my practice behaviors actively challenge power imbalances and involve marginalized communities? How do I extend my responsibility beyond individual clients and advocate for changes in local, state, and national policies and practices? (Fisher-Borne et al., 2015)

In addition, Sisneros et al. (2008) propose the following questions to promote what they call "critical reflectivity," which I journaled on throughout the study:

- What do I do on a day-to-day basis that might contribute to inequality?
- What have I learned about how to perceive or how to relate to members of my own group or other groups, and what is the source of that learning?
- What do I know about how to relate to and interpret the behavior of others who occupy social locations (i.e., class, gender, race/ethnicity, sexual orientation, ability, religion) that are similar to, as well as different from, my own?
- What have I learned about how to interpret the behavior of people whose race/ethnicity, sexual orientation, ability, or religion is different from my own? What if I add class and gender/sex to the equation?
- What do I know about my conscious intentions when I interact with a client who is African America, Latino/Latina, Native American, Asian American, biracial or multiracial, or European American; refugees and other immigrants; people who are gay, lesbian, bisexual, transgender, or intersex; and people with disabilities?
- Why do the consequences or outcomes of my actions not fit with or match my good intentions? (pp. 22-23)

Mindfulness, understanding historical context, and challenging stereotypes are other important strategies in the development of cultural humility (Yeager & Bauer-Wu, 2013), strategies which I already used on a daily basis in my own personal practice. Therefore, I also documented my experience using these tools in my research journal.

Definition of Terms

For the purposes of this study, I will use the following definitions:

- **Urban Aboriginal Peoples:** The Prince George Native Friendship Centre (PGNFC) (2015) defines urban Aboriginal peoples as including all who self-identify as such, regardless of status, preferred terminology, and connection or disconnection to home communities. I will use the term "Aboriginal" interchangeably with "urban Aboriginal," and I will use "Indigenous" interchangeably with these two terms when talking about an international context. When talking about specific studies, I will use the terms used in those studies.
- **Caregivers:** According to the *Dictionary of Social Work and Social Care*, a caregiver is "anyone who is the main carer of a child, whether a parent or not" (J. Harris & White, 2013, p. 53). This can include grandparents, parents, aunts, uncles, or foster parents. It is especially important to use a broad definition of caregivers because of the importance of extended family in many Aboriginal communities (Neckoway et al., 2007) and because of the overrepresentation of Aboriginal children in foster care (Sinha et al., 2011).
- **ADHD:** Attention-deficit/hyperactivity disorder (ADHD) is a clinical disorder that involves inattention, hyperactivity, and impulsivity which interferes with daily life and development in two or more settings, such as at home, at school, or with friends or relatives (American Psychiatric Association, 2013). There are three sub-types: predominantly inattentive, predominantly hyperactive-impulsive, and combined. I will use ADHD to refer to this disorder.
- **Child:** According to British Columbian legislation, a child is anyone under 19 years of age (Legal Services Society, n.d.).
- **Mental health:** The Canadian Mental Health Association (2015) defines mental health as "a state of well-being in which the individual realizes his or her own abilities, can cope

with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community" (p. 1).

- **Mental illness:** The Canadian Mental Health Association (2015) defines mental illness as "a recognized, medically diagnosed illness that results in the significant impairment of an individual's cognitive, affective or relational abilities. Mental disorders result from biological, developmental, and/or psychosocial factors and can be managed using approaches comparable to those applied to physical disease (i.e., prevention, diagnosis, treatment and rehabilitation)" (p. 1).

Summary

This chapter introduced the research question, situated my personal location regarding the research question, and reviewed the definitions of terms that are important to this research. The next chapter will review the literature as it pertains to ADHD, trauma, and Aboriginal experiences.

Chapter Two: Literature Review

History of ADHD

The story of the growth of what we today understand as ADHD is complex. Scholars have examined the association of boys' problem behaviors with problematic mothers through popular media (Singh, 2002), the social and economic contextual factors that influenced the diagnosis coming to prominence (M. Smith, 2012), and the medical history of the disorder itself (Barkley, 2015). The scientific starting point of ADHD is considered to have started with Dr. George Still, a British pediatrician who described "an abnormal defect of moral control in children" in 1902 (Lange et al., 2010; Still, 1902); however, the earliest descriptions of symptoms somewhat consistent with modern ADHD symptomatology were described in the 1700s by German physician Melchoir Adam Weikard and Scottish physician Sir Alexander Crichton in separate medical textbooks (Barkley, 2015; Lange et al., 2010). ADHD first appeared in the second edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and was called "hyperkinetic reaction of childhood" (Lange et al., 2010). It was described with one sentence: "The disorder is characterized by overactivity, restlessness, distractibility, and short attention span, especially in young children; the behavior usually diminishes by adolescence'' (American Psychiatric Association, 1968, as cited in Barkley, 2015, p. 10). With advancing research, the disorder was refined through successive editions of the DSM (Barkley, 2015) until we have the current definition according to the 5th edition (American Psychiatric Association, 2013).

The ADHD Debate

ADHD has oftentimes generated heated debate globally among academics and practitioners, and within the general public. The goal of this research is not to take sides in this

debate but to emphasize the critical importance of listening to the views and beliefs of Aboriginal peoples, who have thus far been largely excluded from it. Therefore, an extensive review of the literature regarding this debate is beyond the scope of this research. I will focus instead on summarizing the leading scholars and practitioners in their respective fields, as well as giving examples.

Overall, the debate regarding ADHD is broadly divided between those who believe it is a valid medical diagnosis and those who argue that it is a cultural or social construction. Singh (2002) called these two camps the biological approach and environmental explanations, which I will use here.

Biological Approach

The dominant discourse regarding ADHD is rooted in the biomedical perspective, which views ADHD as a neurological condition (American Psychiatric Association, 2013). An International Consensus Statement was published in 2002 and signed by over 50 scientists saying that ADHD is a "valid," "real," and "genuine" disorder supported by scientific evidence (Barkley et al., 2002). Some of this scientific evidence includes brain imaging studies which demonstrate that there are differences between ADHD patients and controls (Qiu et al., 2011; Yu-Feng et al., 2007) and twin studies which suggest a genetic basis for the disorder (Hudziak et al., 2005). In a review of the research, Tarver et al. (2014) highlighted several etiological factors that have been investigated, including genetics, brain structure, pre-natal smoking, and prematurity and low birth weight. Those supporting this perspective also point out that ADHD has been identified across cultures around the world (Azevêdo & Caixeta, 2009; Azevêdo et al., 2020; Bauermeister et al., 2010; Caixeta et al., 2010; Caixeta et al., 2012). In a meta-regression analysis, Polanczyk et al. (2014) found that geographic location is not associated with the variability in the

prevalence of ADHD, and these scholars posit that this suggests that culture does not influence the etiology of ADHD.

Environmental Explanations

Medicalization is the process through which normal human behaviors come to be defined as medical issues and is considered a form of social control (Ramey, 2018). Scholars in the fields of psychiatry and education have expressed concerns regarding medicalization and its consequences (Freedman & Honkasilta, 2017; Sjöberg & Dahlbeck, 2017; Timimi & Taylor, 2004; Visser & Jehan, 2009). The influence of pharmaceutical companies and rapid technological change have been identified as contributing to the medicalization of "normal" childhood behaviors (Kristjánsson, 2009; Timimi & Taylor, 2004). Peter Conrad is an American sociologist who has extensively explored medicalization, including the globalization of ADHD as a diagnosis. He argues that this is driven by the transnational pharmaceutical industry, the influence of Western psychiatry, the growing usage of DSM criteria rather than ICD criteria, the internet's power in propagating health related information, such as symptom checklists that facilitate self-diagnosing, and advocacy groups which raise awareness about ADHD in different parts of the world (Conrad & Bergey, 2014). From this perspective, diagnosing a child with ADHD is about controlling behavior that is not considered socially acceptable (Kristjánsson, 2009). Indeed, qualitative research has found that teachers' access to more non-medical means of social control over students—such as suspension and expulsion—is associated with less reliance on pharmaceuticals (Claudia, 2004).

Others point out that medicalization is not sufficient to understand the growing power of ADHD in our society (Comstock, 2011; Kristjánsson, 2009). Comstock (2011) posits that the increase in the number of children and youth diagnosed with ADHD can be explained by the rise

of societal standards of rational self-management that leads people to choose to engage in the ADHD discourse to open new possibilities for themselves and their identity. Similarly, Kristjánsson (2009) argues that subscribing to an ADHD diagnosis seems to be linked to a Western liberal conception of self. This conception of self includes excessive individualism which creates emotional vulnerability. It is upon this emotional vulnerability that industries supposedly can sell remedies to help people achieve a certain normative standard of behavior and performance (Kristjánsson, 2009). In addition, many have urged caution against the use of Western instruments, such as the screening tools used for diagnosing mental illnesses, with different cultural groups because of differing norms regarding behavior (Catale et al., 2015; Paalman et al., 2013; Thorell et al., 2013), and Pickering and Nie (2016) have challenged the idea that ADHD being identifiable in different cultures is evidence for a biological basis of the diagnosis by arguing that culture is not inevitably a force of difference.

ADHD and Trauma

As already mentioned, psychiatrists, pediatricians, practitioners, and others in the academic community speculate that trauma may be misdiagnosed as ADHD. This speculation is related to the impacts of complex trauma. Complex trauma is defined as exposure to prolonged or chronic adverse experiences within the context of the caregiving system that disrupts children's development (e.g., neglect, physical abuse, sexual abuse, etc.) (D'Andrea et al., 2012; van der Kolk, 2005). Impacts can include difficulties with regulation of affect and impulses, memory and attention, self-perception, interpersonal relations, somatization, and systems of meaning (van der Kolk et al., 2005). As such, children and youth impacted by complex trauma are more often diagnosed with disorders such as ADHD, separation anxiety disorder, or oppositional disorder than they are with post-traumatic stress disorder (PTSD) (Ackerman et al.,

1998). Children impacted by complex trauma have been found to report lower mutual trust in interpersonal relationships, more self-blame for negative events, more negative belief in being victimized, lower self-esteem, more behavioral difficulties, and greater use of emotion-dysregulated coping strategies than children who have experienced a traumatic event not related to abuse or children with no trauma (Ma & Li, 2014). In a meta-analysis, Lavi et al. (2019) found that maltreated children have more difficulties with emotion reactivity and emotion regulation.

In contrast, PTSD involves exposure to actual or threatened death, serious injury, or sexual violence, with symptom criteria of reexperiencing, avoidance, and hypervigilance (American Psychiatric Association, 2013). It has been argued to not be developmentally sensitive (van der Kolk, 2005), and as such, many scholars have argued that a new psychiatric diagnosis is needed to account for the unique sequelae of exposure to complex trauma (D'Andrea et al., 2012; van der Kolk, 2005). Developmental trauma disorder has been proposed and is currently under clinical and scientific investigation for its utility (DePierro et al., 2019; Ford et al., 2018; van der Kolk et al., 2019). Moreover, the World Health Organization issued the latest revision of the International Classification of Diseases, ICD-11, in July 2018. This revision replaces the diagnosis of PTSD with PTSD and complex PTSD (CPTSD), which adds three disturbances in self-organization to the diagnostic criteria, called emotional dysregulation, interpersonal difficulties, and negative self-concept (Brewin, 2020).

Regarding ADHD specifically, many scholars have investigated the relationship between an ADHD diagnosis and adverse childhood experiences (ACEs). ACEs include all types of abuse, parental mental illness, divorce, incarceration, substance use, and domestic violence. The original ACEs study investigated childhood experiences and health status and behaviors later in life, and the researchers were the first to demonstrate a graded relationship between exposure to

abuse or household dysfunction in childhood with leading causes of death in adulthood (Felitti et al., 1998). ACEs have since been linked to several poor physical and mental health outcomes in adulthood such as depression, alcoholism, drug use, suicide attempts, and heart and liver disease (Dube et al., 2001; Dube et al., 2003; Hughes et al., 2017). Intergenerational trauma has similarly been associated with negative physical and mental health outcomes (Barker et al., 2019; Bombay et al., 2014; McQuaid et al., 2017). Blodgett and Lanigan (2018) argue that discussions about ACEs and trauma need to be linked due to the emergent nature of mental health needs for children. This is arguably especially the case for Aboriginal children as research suggests that ACEs are likely more prevalent among Indigenous peoples due to the consequences of colonialism (Warne et al., 2017).

Quantitative research has found that children exposed to ACEs are more likely to be diagnosed with ADHD (Baglivio et al., 2017; Hunt et al., 2017) and children with two or more ACEs are more likely to have the diagnosis than those who just have one (Bethell et al., 2014). Other research has found a dose-response relationship with ACE scores and learning problems, behavior problems, and school absenteeism (Burke et al., 2011; Stempel et al., 2017). Using a longitudinal sample, Jimenez et al. (2017) found that ACEs occurring before ages 5 and between 5 and 9 were both associated with an ADHD diagnosis at 9-years-old. Research has also found that the number of ACEs experienced is associated with greater academic failure, attendance problems, school behavioral concerns (Blodgett & Lanigan, 2018). ACEs are associated directly with high school drop out, as well as indirectly through externalizing behaviors and poor reading achievement (Morrow & Villodas, 2018). In addition, multiple losses in a child's life increases the odds of them being diagnosed with ADHD (H. W. Harris & Zipperlen, 2011). However, a study with male juvenile detainees found that ACE scores did not predict ADHD but instead

predicted PTSD, anxiety disorders, depressive disorders, and suicidality (Bielas et al., 2016). The scholars speculated that their results might have been impacted by ceiling effects due to the high rate of ACEs and externalizing disorders in their sample.

Research using measures other than the ACE questionnaire have found that child abuse, adverse living conditions, and school anxiety could contribute to behavior problems among children diagnosed with ADHD (Çoban & Tan, 2020; Fuller-Thomson et al., 2014; Schilpzand et al., 2018; Zou et al., 2019). Other scholars have used brain imaging techniques. Park et al. (2016) tried to distinguish between the impacts of trauma exposure and ADHD by using brain diffusion tensor imaging. They found that ADHD and trauma exposure had additive adverse effects on white matter in various parts of the brain.

Research with adults has found that adult inpatients with major depression and comorbid ADHD have higher trauma scores than adults with just major depression (Erdoğan et al., 2020) and that having experienced childhood trauma is associated with persistence of an ADHD diagnosis into adulthood (Çoban & Tan, 2020). In adult inpatients with alcohol use disorder, the severity of ADHD symptoms was associated with the severity of dissociative symptoms, and this relationship was partially mediated by physical abuse (Evren et al., 2017). The severity of ADHD symptoms was also related to the severity of PTSD symptoms, and this relationship was mediated by childhood trauma, particularly emotional abuse (Evren et al., 2016). Finally, soldiers in the United States with pre-deployment ADHD were found to have a higher risk of developing post-deployment PTSD in a longitudinal study (Howlett et al., 2018).

Research has also explored the impact that different types of trauma has on psychiatric diagnoses. Ferrer et al. (2017) found that physical abuse was associated with ADHD and emotional abuse and sexual abuse were associated with borderline personality disorder (BPD)

and comorbid BPD-ADHD. Interestingly, this study found no significant difference between ADHD and a control group regarding childhood trauma histories (Ferrer et al., 2017); however, this could be related to the fact that the control group was not considered a healthy control group because they presented with a significantly higher number of BPD criteria than the ADHD group.

Children diagnosed with ADHD may also be more likely to experience traumatic events due to difficulties with impulsivity and self-regulation. McQuade et al. (2018) found that children diagnosed with ADHD are at a higher risk of relational victimization via social problems such as peer rejection, lack of reciprocal friendships, and annoying and intrusive social behavior, while those with co-occurring oppositional defiant disorder (ODD) diagnoses are likely to be physically victimized and experience relational victimization via physical aggression and relational aggression. ADHD has also been identified as a risk factor that may contribute to traumatic injuries. High levels of ADHD were found among children presenting to emergency services at a hospital in Turkey for unintentional injury (İz & Çeri, 2018), and among children who experienced penetrating eye injuries (Bayar et al., 2015) and injuries to the head and neck (Karayağmurlu et al., 2019).

Family physicians, rather than specialists such as psychiatrists, provide the majority of the diagnoses for ADHD in Canada (Vasiliadis et al., 2017). Evidence suggests that general practitioners are accurate less than half the time (Su et al., 2011) and that psychiatrists and general practitioners agree about 40% of the time for other mental health disorders (Canuto et al., 2016). Research has found that professionals in general practice settings may have a limited interest or knowledge of mental health issues (Fleury et al., 2016) and that they may screen for

anxiety and trauma less than those in mental health settings (Spitzer et al., 2017). This may lead to a higher rate of misdiagnosis.

Experiences of ADHD

Qualitative research has been conducted with children, youth, adults, and caregivers across the world. I will focus on the literature concerning caregivers because that is the population included in this research. Qualitative research has found several themes regarding parenting children diagnosed with ADHD, including increased stress (Corcoran et al., 2017a; Kildea et al., 2011; Leitch et al., 2019; Mofokeng & van der Wath, 2017); distress when having to manage social stigma (Cronin, 2004; Leitch et al., 2019); impacts on family life and relationships (Leitch et al., 2019; Mofokeng & van der Wath, 2017); and the challenge of balancing the benefits and costs of medications (Corcoran et al., 2017b; Hansen & Hansen, 2006).

The studies in the preceding paragraph were either done with members of the dominant culture or else ethnicity was not mentioned at all. Some exceptions include a study conducted by Araujo et al. (2017) in the United States with Latino caregivers. They found that racism impacted the caregivers' ability to seek help for their children; that cultural values created conflict within families related to childrearing; and that language barriers made it difficult for caregivers to communicate with their children. This study also found that grandparents played a large role in caring for children and that caregivers blamed themselves for their children's problems (Araujo et al., 2017). In another study conducted in the United States, Blum (2011) found that women of color raising children with ADHD felt like race played a role in schools pressuring them to put their children on stimulant medications. These studies suggest that visible minorities may experience disorders such as ADHD differently than those from the dominant culture.

Paradigms of Mental Health and Mental Illness

Paradigms are systems of thought that guide action (Creswell & Poth, 2018) and have been defined by the *Oxford English Dictionary* as "a worldview underlying the theories and methodology of a particular scientific subject" (Paradigm, n.d., para. 1.1). Mental health and mental illness are currently predominantly understood from a Eurocentric Western paradigm, which focuses on individual pathology and deficits (Mussell et al., 2004; Vukic et al., 2011). However, this is not the only way to view mental health and mental illness. Baskin (2007) notes that there are various elements that are common among many Aboriginal peoples that make up a fairly generalizable worldview, with the disclaimer that Aboriginal peoples are not a homogenous group and that individuals and communities have many distinct languages, cultures, and beliefs. For instance, mental health is often viewed within a wholistic framework that includes the wellbeing of mind, body, and spirit; the importance of relationships; and a connection to the natural environment (Carriere & Richardson, 2012). For many Aboriginal peoples, poor mental health comes from a lack of balance in physical, emotional, spiritual, and mental aspects, while a Western approach often ties poor mental health to dysfunctional neurological processes (Mussell et al., 2004). In other words, an Aboriginal paradigm of mental health and mental illness is based on wellness while a Western paradigm is based on illness (Linklater, 2014).

Aboriginal Experiences of ADHD

Global research on Indigenous peoples and ADHD has largely been conducted in the United States, Brazil, Israel, and Australia. In the United States, much of the research has been deficit-based. For instance, studies have explored the prevalence and social contextual risk factors for stimulant misuse among American Indians (Spillane et al., 2017) and the co-

morbidity of alcohol and drug use with affective and disruptive disorders (Abbott, 2006). Neither of these studies include a discussion on colonialism and the effects of intergenerational trauma.

In Brazil, a study using a child psychiatrist conducting clinical interviews with Indigenous parents found that symptoms of ADHD were present among their children (Azevêdo & Caixeta, 2009; Caixeta et al., 2010). Another study using a nurse to administer questionnaires in villages in the Amazon with the Karajá ethnic group found that the prevalence of ADHD symptomology was similar to global prevalence (Azevêdo et al., 2020). However, both parental and teacher reports of clinical significance are needed for a diagnosis of ADHD. In this study, only 1.1% of children were reported by both guardians and teachers to have symptoms that negatively impacted them (Azevêdo et al., 2020). This is compared to an average global prevalence of 5.3% adopted in this study. These studies had a limited consideration of cultural perspectives regarding these symptoms. Azevêdo et al. (2020) included this statement while talking about a case study:

> The child was examined considering the values and expectations of the Karajá culture. The Karajá child is free to do virtually anything he wants until he/she is 7 years old. He/she enters the school at this age, and he/she is literate in the native language and only then learns Portuguese. During class, children can go out to bathe in the river and return later. To an unsuspecting non-indigenous observer, almost all Karajá children—disruptive and noisy during class—would be labelled as having ADHD. However, in their culture, this is allowed and does not prevent education from taking place according to the established curriculum. (p. 379)

This is the extent that culture is discussed until the researchers speculated, “How, in a culture that allows children total freedom, are parents bothered by ADHD-like behaviour?” (p. 381) and

used the observation that parents came to them for help as evidence that ADHD can be diagnosed among the Karajá and so is not a cultural construct. This arguably illustrates Timimi's (2014) point that psychiatric diagnoses may impose Western beliefs on other cultures as the scholars were using Western definitions rather than exploring how the Karajá explained their children's behavior. They also did not question the power dynamics involved that may have influenced the Karajá coming to them.

The research conducted in Australia is an exception to the deficit-based and culture blind trend. Recently, there have been calls to explore Aboriginal perspectives of ADHD and stimulant medication use (Ghosh et al., 2015). Loh et al. (2017) conducted a qualitative research study with 27 Australian Aboriginal participants with the goal of exploring Aboriginal perspectives of ADHD as a Western concept and approaches to treatment and management of symptoms. Loh et al. found that Aboriginal participants largely recognized ADHD as a legitimate disorder with negative consequences for the child and others. Interestingly, participants attributed the cause to Indigenous peoples eating a non-Indigenous diet. Some participants had positive experiences with medications, but the majority did not support a pharmacological approach and expressed a need for culturally appropriate treatment. However, this research also did not include a consideration of intergenerational trauma. This is unfortunate considering that Australian academic pediatrician David Isaacs (2006) expressed concern that the diagnosis of ADHD and the use of stimulant medications are being used as a "quick fix for complex problems" (p. 544).

I was only able to find one study in Canada which included Aboriginal perspectives on ADHD. This was an ethnography conducted with high prescribing doctors in Manitoba by Michael J. Oldani (2009), a scholar with a PhD in Medical Anthropology from Princeton University. One Aboriginal focus group participant called medications for ADHD "nothing more

than residential school in a bottle" (Oldani, 2009, p. 143). This participant explained that, like residential schools, the purpose of medications is to try to make Aboriginal children conform to Western standards of behavior. This highlights that a greater understanding is needed regarding how Aboriginal peoples view and experience ADHD in Canada, which this research begins to explore.

Summary

This chapter reviewed the literature. First, it provided a brief history of ADHD. Second, it reviewed the debate surrounding ADHD. Third, it discussed the research on ADHD and trauma. Fourth, it explored the experiences of living with ADHD for non-Aboriginal peoples. Fifth, it looked at paradigms of mental health and mental illness. Finally, it considered the literature on the experiences of Aboriginal peoples with ADHD. The next chapter will describe the research design.

Chapter Three: Research Design

Theoretical Orientation

I used an exploratory qualitative approach situated within an anti-oppressive framework for this research. Qualitative research methods are concerned with the meaning that people give to a social phenomenon (Creswell, 2014) and can be distinguished between small q and big Q approaches. Small q qualitative research is located within a positivist framework. Positivism is a philosophical worldview focused on finding objective and measurable truth, and it has been critiqued as contributing to the colonization of Indigenous ways of knowing (Martin, 2012). Big Q qualitative research views the research process as more subjective and interpretive, and they have been argued to respect the oral tradition of many Aboriginal cultures (Kovach, 2010). Terry et al. (2017) use the examples of an archaeologist and a sculptor to illustrate the difference. An archaeologist is looking for pre-existing answers; a sculptor is interacting with the raw materials to produce a sculpture that is a product of the interaction between the sculptor's skills and the raw materials. I used the latter approach, which I will describe in the following.

There are a variety of qualitative approaches that vary in their research focus, research problem, and procedures (Creswell, 2018). I chose to use an exploratory approach due to its flexibility. It does not have a standard process or associated theoretical underpinnings, and can be defined as exploration of social or psychological life for the purposes of discovery (Jupp, 2006; Stebbins, 2001). An important feature of exploratory research is that the researcher is considered an explorer (Stebbins, 2001), which I chose to interpret as meaning that the researcher takes a position of curiosity rather than that of an expert discovering and defining knowledge. Indeed, maintaining a position of curiosity and a learner's stance regarding

expanding knowledge of Aboriginal culture, traditions, and ways of being has been identified as a tangible practice tool of anti-oppressive practice (Cowie, 2010).

When approaches are flexible in which theoretical and philosophical underpinnings can be applied, Terry et al. (2017) point out that researchers must be explicit about their theoretical orientation and data analysis approach. Therefore, I chose anti-oppressive practice as a theoretical framework to compliment my exploratory approach. Anti-oppressive practice has been considered by nursing, social work, and psychology since the mid-1990s and it is an emerging framework in the medical field (Veltman & La Rose, 2016). Anti-oppressive social work practice was a response to the failures of cultural competence models, which view the challenges encountered in social work practice with visible minorities and other ethnic groups as simply stemming from a lack of knowledge about clients' cultures (Jeffery, 2009). This is problematic because it neglects a consideration of power imbalances. Instead, an anti-oppressive approach places power imbalances as central to understanding oppression in social work (L. Brown & Potts, 2005; Campbell, 2003). Mullaly and West (2018) group an anti-oppressive approach with what they call "progressive social work" approaches, also including feminist social work, Indigenous approaches, post-colonial theory, and structural approaches. Progressive social work perspectives and approaches are based on conflict theory, which views society as being stratified by a range of social divisions such as class, gender, race, and ability, that both engender and embody discrimination and inequality (Mullaly & West, 2018). From this perspective, oppression is viewed as the major cause and explanation of social problems (Mullaly & West, 2018) and anti-oppressive practitioners are concerned with the oppression that can occur at different levels, such as individual or institutional (Veltman & La Rose, 2016).

Regarding mental health practice, several principles of anti-oppressive practice have been identified. These include the participation of service users in mental health services, using language that is accessible and free of jargon, and deconstructing the medical model with families (Larson, 2008). Qwul'sih'yah'maht and Kundouqk (2009), two Aboriginal scholars, identify three key elements of anti-oppressive social work practice that can be used to inform an anti-oppressive approach to research: (a) acknowledge the social, cultural, and historical context of families seeking services; (b) include an analysis of power; and (c) involve the recognition that knowledge is socially constructed. Other scholars have also articulated an anti-oppressive approach to research in social work. L. Brown and Potts (2005) describe three emerging tenets, including (a) a commitment to social justice in both process and outcome; (b) an understanding that research is not a process of discovering knowledge but a political process of rediscovering it; and (c) a commitment to shifting the power to those marginalized from it. Strier (2007) indicates that the goal of such research is to study oppression and develop knowledge that can support people in their resistance of oppression.

Clinical mental health practice relies on medical, biological, and psychological approaches, leading some to point out a dissonance between anti-oppressive principles and clinical mental health practice (Larson, 2008). However, Rubin (2020) argues that anti-oppressive clinical practice can be compatible with evidence-based practice, despite the former being based on post-modern ideology which rejects scientific evidence. He does this by pointing out how acting without scientific evidence can inadvertently increase oppression, such as in the case of deinstitutionalization, and how scientific evidence can reduce oppression, such as in the case of reducing stigma of certain mental health disorders by acknowledging them as brain disorders. Rubin suggests that,

> Social workers committed to social justice should bear in mind how an extreme, ideological approach to AOP [anti-oppressive practice] can have unintended consequences, even if that approach meets the clinician's need to feel au courant with the profession's righteous emphasis on social justice. Moreover, social workers committed to social justice might consider the proposition that the best way to promote social justice is through practices that have the best available scientific evidence supporting their beneficial impact on oppressed people. (p. 629)

Anti-oppressive practice is not free of criticism. For example, many have highlighted the challenge of translating anti-oppressive principles into practice (Baskin, 2016; Jeffery, 2009; Sinclair & Albert, 2008). Indeed, research with Master of Social Work graduates in Canada found that although social justice values were endorsed by the program and the profession, graduates reported limited opportunities to apply anti-oppressive practice in field education (Bhuyan et al., 2017). Moreover, many scholars have highlighted different examples of how social work has inadvertently perpetuated oppressive practices despite social justice values, such as against Aboriginal people in Canada with the child welfare system (Crichlow, 2002; Blackstock, 2009, 2011). Finally, Baskin (2016) points out that anti-oppressive practice approaches are grounded in Western worldviews. However, she also argues that such theories can strengthen allies in social work practice (Baskin, 2016). Therefore, considering the critique of ADHD specifically and psychiatric diagnoses in general regarding Aboriginal peoples, an anti-oppressive framework is arguably ideal for me as a non-Aboriginal person to explore the experiences of Aboriginal caregivers with children diagnosed with ADHD.

Participants

Sample size can be a contentious issue in qualitative research. Terry et al. (2017) made broad recommendations for Masters projects involving interviews as 6 to 15. Commonly, researchers refer to saturation, which is used as a guideline for when to discontinue data collection. However, saturation has been inconsistently conceptualized and operationalized (Saunders et al., 2018). Malterud et al. (2016) propose the concept of information power instead. They suggest that the higher information power a sample holds, the less participants needed. Information power is influenced by the study aim, the sample specificity, the use of established theory, the quality of dialogue, and the analysis strategy (Malterud et al., 2016). If the study aim is narrow, if the sample holds characteristics that are highly specific to the study aim, if theory is applied, if the quality of dialogue between participants and researcher is strong, and if the analysis strategy focuses on in-depth narratives, fewer participants are needed (Malterud et al., 2016). In this research, the study aim was narrow, focused on the experiences of Aboriginal caregivers of children diagnosed with ADHD in Northern British Columbia rather than caregivers in general; the sample was highly specific to the study aim; an anti-oppressive framework was applied; and the quality of dialogue was strong. This suggests that sufficient information power can be achieved with a smaller sample size. The only factor that suggests a larger sample size may be needed is the analysis strategy. This research relied on cross-case analysis rather than in-depth analysis of a few cases. As such, I aimed to include 6 to 10 participants in this study. However, due to the narrow study aim and the added stress of dealing with a pandemic, there were not many caregivers who had the emotional capacity to participate in this research at this time. Therefore, I chose to stop recruiting at four participants. Data was collected from March 2019 to September 2020.

In my sample, there were four female identifying participants ranging in age from 38 to 50 with an average age of 44. Three had bachelor's level degrees and the last had some college/university. Their children ranged in ages from 5 to 15, with an average age of 10.75. They were diagnosed with ADHD between ages 5 to 8 with an average age of 6.5 years. One child was diagnosed by a psychiatrist, the second by a psychologist, the third by a pediatrician, and the last participant was not sure if her child had been officially diagnosed, but their pediatrician had prescribed stimulant medications. Three of the children were male and one was female. One participant identified as First Nations, the second indicated that she did not have an ethnocultural identity but endorsed an Indigenous background, the third identified as Aboriginal, and the final one indicated that she was Status Tsay Keh Dene. Regarding household income, two made between $40,000 and $60,000, and the other two made over $80,000.

Participants were selected based on criterion sampling with the following inclusion criteria:

- Participants were at least 19 years old;
- Participants self-identified as Aboriginal, as already defined for the purposes of this research;
- Participants were living in Northern British Columbia; and
- Participants were caregivers of children diagnosed with ADHD by a physician.

Participants were recruited through recruitment posters (see Appendix A) posted at the Prince George Native Friendship Centre (PGNFC) and shared on Facebook pages, including the PGNFC's and online support groups for parents of children with ADHD in Northern BC. They were encouraged to contact me if they were interested in learning more about the study. Participants were then provided with a letter of information via email (see Appendix B).

Data Collection

Data was initially collected through face-to-face individual interviews. However, the COVID-19 pandemic necessitated revisions to the research protocol to ensure the safety of participants. Therefore, one interview was conducted in person prior to the pandemic and the other three were conducted over the phone. Participants were welcomed to invite family members and Elders to be present during the interview. Baskin (2016) suggests avoiding direct questioning and instead recommends that researchers introduce the research topic, explain why they want to do the work, and invite participants to share their experiences with the topic. Therefore, this is how I began interviews. I also had a semi-structured interview guide to provide myself with some guidelines about the information I sought to gather (see Appendix C). A demographic form was used to collect key demographic information (see Appendix D). Participants were given the option of filling the form out themselves or having me write down the answers they dictated.

Advancements in technology have had many benefits for research but have also made it more challenging to protect the privacy and confidentiality of participants (Research Ethics Officer, n.d.). Therefore, I addressed these emerging issues in my data management plan, which is based on the recommendations of the Research Ethics Officer (n.d.). First, individual interviews were digitally recorded and stored on an USB flash drive. The USB flash drive was encrypted using Bitlocker and stored in a locked cabinet in my office at my personal residence. The demographic forms were stored in a separate unmarked file in this locked cabinet because they indicated which pseudonym relates to which participant. Second, the signed consent forms were stored separately from the demographic forms and the USB flash drive in the locked drawer of my desk. Third, I transcribed all the interviews personally. The interview transcripts were

stored on my password protected computer and the files were encrypted. Fourth, the audio files and interview transcripts were identified using pseudonyms. All identifying information was removed from the interview transcripts. The demographic form was the only document which identified which pseudonym is associated with which participant. Fifth, after the research is completed, the interview transcripts will be transferred to the encrypted USB flash drive and stored in a locked cabinet in my office at my personal residence. The transcripts will be deleted from my computer. Finally, the data will be destroyed five years after the date of my defense.

Data Analysis

Data was analyzed using six-phase thematic analysis as originally described by V. Braun and Clarke (2006) and further detailed in Terry et al. (2017). Thematic analysis has been variously defined and, depending on the theoretical orientation of the researcher, can be considered small q or big Q (Terry et al., 2017). The flexibility of thematic analysis has been identified as a strength (V. Braun & Clarke, 2006; Terry et al., 2017), especially for novice researchers (V. Braun & Clarke, 2006), and also means that researchers need to be very explicit about their theoretical orientation and data analysis approach (Terry et al., 2017). Theoretical orientation has already been described, and based on this, several choices were made regarding data analysis. These choices included whether to use an inductive or deductive approach, and whether to focus semantically or latently during coding. First, an inductive approach to data analysis is bottom up and starts with the data, and a deductive approach is top down and starts with theoretical concepts and theories through which a researcher sees the data. Considering that my theoretical orientation is exploratory and anti-oppressive, and that my research question focuses on the experiences of Aboriginal caregivers, I used an inductive approach to coding. Second, semantic coding captures explicit meaning and latent coding captures implicit meaning.

Inductive approaches are more bound by semantic meanings (Terry et al., 2017); therefore, I focused on semantic coding.

The six phases of thematic analysis are not linear but rather iterative and recursive, with researchers often moving back and forth between phases (Terry et al., 2017). However, I will describe the stages linearly in the following for clarity, with the understanding that I often moved between the stages in a non-linear fashion.

The first phase is familiarization with the data. It involves the researcher immersing themselves in the data. Terry et al. (2017) says that the researcher should "get into a mode of reading that actively engages with the data as data" (p. 23). This involves reading and rereading the data, as well taking a curious stance and asking questions (Terry et al., 2017). In this phase, I transcribed all interviews myself rather than hiring a transcriber. Once I finished transcribing them initially, I listened to them once more to check my transcription, as well as to increase familiarization. I also kept notes in a research journal about my initial analytic observations when going through individual transcripts, as well as made notes about my observations from the entire data set. For example, some of my notes regarding individual transcripts include "talked about worry about discrimination despite never having experienced it…internalized shame?" and "directly attributed ADHD to her son's experience of complex trauma." Notes regarding my analytic observations of the entire dataset include "no one talked about culture" and "a big theme seems to be accessibility of supports that are impacted by different factors." At this point, I also sent transcripts to be member checked by participants, which has been identified as a critical element in quality qualitative research (Guba, 1981). Two of the four participants wanted to member check their interviews. They did not make any additions, changes, or subtractions to the transcripts.

The second phase is generating codes. Terry et al. (2017) defines coding as "the systematic and thorough creation of meaningful labels attached to specific segments of the dataset" (p. 26). Terry et al. recommend that researchers find the tools that work for them to help them code. For me, I chose to use flashcards, indicating line numbers and participants on the backs, with a corresponding file on my computer where coded segments were collated. As recommended by V. Braun and Clarke (2006), I coded for as many potential themes as possible at this stage. Some examples of initial codes include "question ourselves because unsolicited advice," "problems identified in school," "worry about side effects," "grew up with shame of Indigenous identity," "too much dealing with own trauma," and "listen to their voice."

The third phase involves constructing themes. Terry et al. (2017) describe it as a process of forming and identifying patterns. They recommend using visual aids such as thematic maps or tables to help form distinctive themes that tell a story about the entire dataset. I sorted flashcards into a table that I could physically interact with to visually represent themes and their relationships to each other (see Figure E1). These are called candidate themes (Terry et al., 2017). See Table E1 for selected early candidate themes and example codes.

The fourth phase is reviewing. Terry et al. (2017) call this a "quality control" exercise to ensure that the themes fit with the data and the entire dataset, as well as that they answer the research question. In this phase, I read each of my flashcards within each theme to ensure that they indeed formed coherent themes. For example, I had an early candidate theme called "school experiences." However, upon reviewing this theme, I found that there was significant overlap between the codes contained within it and other themes, such as accessibility regarding information, attitudes, systems, and advocacy. Therefore, I broke that theme down and reorganized the coded segments into the corresponding themes in which they fit best. See Figure

E2 for a thematic map that illustrates this process. I also returned to the interview transcripts and read them again to ensure that the themes accurately reflected the data. At this point, I coded any additional data that were missed in earlier stages.

The fifth phase involves defining and naming themes. It is at this point that Terry et al. (2017) indicate that the researcher moves into an interpretive stance rather than a summative one. To do this, I began to write a narrative and detailed analysis for each theme, identifying what was important and why. This helped me further define each theme and ensured that there was not too much overlap between the different themes. Moreover, I also wrote theme definitions for each theme. Theme definitions are short summaries of the core idea of each theme and can help the researcher determine if a theme is too thin, if it lacks coherence, or if it is too complex to be a unified theme (V. Braun & Clarke, 2006; Terry et al., 2017). See Figure E3 for an example of one of my theme definitions. In addition, I also brainstormed names to give the themes in the final analysis. At this stage, I organized second interviews with participants to review the draft of the findings. However, the participants who had expressed interest in doing so declined due to too many things going on in their lives at the time.

The final phase in thematic analysis is producing the report. It is in this phase that data analysis is connected to the scholarly literature (Terry et al., 2017). Terry et al. (2017) talk about two different styles of writing around data in thematic analysis. The first is illustrative, where data extracts are primarily used as examples, and the second is analytic, where specific data extracts are discussed and used to support analytic claims. Most reports use a combination of the two to illustrate the story the researcher aims to tell with the data and to make an argument regarding the research question (V. Braun & Clarke, 2006; Terry et al., 2017). I chose to include

findings and discussion in two separate chapters, the former focusing on an illustrative way of presenting data extracts and the latter becoming more analytic.

Aboriginal Advisory Committee

Although qualitative research is often argued to be appropriate for use with Indigenous peoples (Kovach, 2010), it also risks being interpreted by the researcher according to a Western worldview (K. L. Braun et al., 2013). Therefore, an Aboriginal Advisory Committee was established at the request of the Prince George Native Friendship Centre (PGNFC) to ensure ethical research was being conducted. Originally, this Committee was comprised of two Elders, a School District 57 employee, and an Executive Director of a mental health agency in Prince George. However, the COVID-19 pandemic and unexpected situations with family unrelated to COVID-19 impacted the ability of these individuals to participate. Instead, an Aboriginal teacher with many years of experience in a school district in Northern British Columbia and the aforementioned Executive Director participated in conversations over Zoom with myself to give feedback on the research findings and dissemination strategies.

Dissemination

The results will be disseminated in two ways. First, participants will be given the opportunity to have my thesis mailed or emailed to them. They will be informed that it will be available in the University of Northern British Columbia (UNBC) library if they do not want a copy themselves. I will also provide a bound copy to the Prince George Native Friendship Centre (PGNFC). The results may also be published in journal articles and books. Second, I will set up a table at three different community events, COVID-19 permitting. These community events will be determined after consultation with my supervisor, supervisory committee, Aboriginal Advisory Committee, and the PGNFC. To make the research findings more accessible for

community members, I will create one-page summaries of key findings which will be distributed at these events. These summaries will also be presented to different service providers in the community, including physicians, mental health practitioners, and school staff. In addition, further dissemination strategies may be implemented based on consultations with the Aboriginal Advisory Committee.

Ethical Considerations

Ethics approval for this research was granted by the Prince George Native Friendship Centre (PGNFC) (see Appendix F), School District 57 (see Appendix G), and the University of Northern British Columbia's (UNBC) Research Ethics Board (REB) (see Appendix H). Research ethics approval was obtained from the PGNFC prior to seeking approval at UNBC, as outlined in the PGNFC's research protocols (Prince George Native Friendship Center, 2015).

There were several ethical considerations in this research. First, research has historically been used as a tool of colonialism and exploitation against Aboriginal peoples (Durst, 2004), and continues to be conflated with colonialism for many (L. T. Smith, 1999). It is therefore vital that any research done with Aboriginal peoples be conducted according to their rules and respect their rights, culture, and knowledge (Basile et al., 2014), keeping in mind that Aboriginal peoples come from many diverse backgrounds. Therefore, I followed the protocols laid out by the PGNFC in their research charter and protocols document (Prince George Native Friendship Center, 2015). I also adhered to the four Rs of Aboriginal research ethics as described by Kirkness and Barnhardt (1991), which includes respect, reciprocity, relevance, and responsibility. For example, small gifts are important in many Aboriginal cultures as a way to acknowledge the relationship and show respect for the stories shared (Kovach, 2010), and the PGNFC recommends compensating participants in some way (E. Anderlini, personal

communication, March 1, 2018). As such, Tim Hortons gift cards with a value of $10 were given or emailed to participants immediately following face-to-face interviews. The *Tri-Council Policy Statement* defines incentives as anything that is offered to participants to encourage their participation (Canadian Institutes of Health Research et al., 2010). Incentives may impact the voluntariness of participation. Originally, compensation was not advertised on the recruitment poster to help facilitate voluntary consent. I did not want to advertise the compensation because my intention with the gift cards was not to encourage participation but to show respect and gratitude to my participants. However, after feedback from my first participant about how hard it is to find time in a day to participate in research, especially with the demands of caring for their children, I decided to advertise the compensation as a gesture of respect and reassurance to those caregivers who wanted to participate but were having to juggle competing responsibilities in their work, family, and social lives.

Second, asking participants to reflect on their experiences with their children may bring up traumatic or distressing memories for them. Therefore, the research questions were designed according to trauma-informed principles. I used the guidelines from the *Trauma-Informed Practice Guide*, including (a) keeping the discussion connected to present functioning and not asking about details of trauma experiences, (b) reminding participants that they can decline to answer or choose to take breaks, and (c) including questions about the individual's strengths (TIP Project Team, 2013). Initially, the research protocol indicated that a counsellor would be available to debrief participants if necessary, after their interview. However, this was premised on the understanding that interviews would be conducted at the PGNFC. The one participant who participated in a face-to-face interview declined to doing an interview at the PGNFC and instead requested the Prince George Public Library. The other three interviews were conducted

over the phone. Each participant was provided with a list of resources in the community either in person or via email. In addition, I provided personalized feedback with participants' consent on available resources based on the challenges each participant described according to my knowledge as a mental health counsellor. For example, I shared Anxiety Canada's website and information about the Bounce Back program and Rolling with ADHD.

Finally, there was and continues to be potential for a conflict of interest to arise. To explain, I work with both Aboriginal and non-Aboriginal families with children diagnosed with ADHD in my position as a mental health counsellor. As such, it was and still is possible to encounter former, current, or future clients during my research. This dual relationship (i.e., as clinician and researcher) may create undue influences, power imbalances, or coercion (Canadian Institutes of Health Research et al., 2010).

There are several scenarios in which a conflict of interest may arise. First, there was the possibility that I could have been approached by my employer to provide services to a former participant in the study in the future. This is addressed within my agency's policies. To explain, it is always verified with clinicians that a dual relationship does not exist before assigning files to them. The nature of the dual relationship is not discussed and so participants' participation in the study would remain confidential. Second, a past or current client of mine could have approached me to participate in the study. To minimize the likelihood of this happening, I did not recruit participants from my own workplace. However, one participant indeed was a former client of mine who approached me about participating in the study. I handled this by disclosing the nature of the dual relationship as part of the informed consent process and left it up to them if they wanted to participate or not, as detailed in the *Tri-Council Policy Statement* (Canadian Institutes of Health Research et al., 2010).

Evaluation Criteria

Tracy (2010) proposes eight characteristics of quality qualitative research that can be applied across paradigms, including (a) that the research topic is worthy, (b) that the study has rich rigor, (c) that it provides a significant contribution, (d) that it considers various ethical issues, (e) that the research has resonance with a variety of audiences, (f) that the study is characterized by sincerity, (g) that study is credible, and (h) that it achieves meaningful coherence. The first four have already been discussed in other sections or will be addressed in the conclusion, and the last can only be evaluated by the discerning reader considering this report in its entirety. Therefore, I will focus on sincerity, credibility, and resonance in the following.

First, sincerity is achieved through reflexivity and transparency (Tracy, 2010). Therefore, as already mentioned, I kept a research journal in which I examined my own biases and how they impacted the research. I completed this research journal before and after each interview, as well as during the data analysis and report writing processes. In addition, I also kept a formal audit trail to track my research activities.

Second, the criterion of credibility refers to the trustworthiness of the findings (Tracy, 2010). I used thick description when reporting the findings, meaning that I provided a lot of detail and concrete examples to illustrate the themes, as well as including direct quotations from the participants. Triangulation is also a method used to achieve sincerity and refers to when two or more sources of data are used to see if they reach the same conclusions (Tracy, 2010). In my study, I used the literature review and the voices of my participants as two sources of data. I would have liked to interview service providers as well but decided that to do so would be out of the scope of a master's thesis.

Finally, resonance refers to the study's ability to affect an audience and can be achieved through aesthetic merit, transferability, and naturalistic generalizations (Tracy, 2010). Aesthetic merit will be achieved using my own enjoyment of storytelling and writing. As for the latter two, as already mentioned, ADHD may affect Aboriginal families at higher rates than the general Canadian population. Therefore, the research findings arguably overlap with the experiences of many Aboriginal peoples, and the vicarious experience readers may get from reading the experiences of Aboriginal caregivers may influence their choices.

Summary

This chapter reviewed the research design that was employed in this study. First, it explored the theoretical orientation by describing the exploratory qualitative approach using an anti-oppressive research framework. Second, the demographics of the participants were described. Third, the data collection process was explained. Fourth, the phases in thematic analysis were described as they relate to this study. The final sections reviewed the use of an Aboriginal Advisory Committee, the dissemination techniques, ethical considerations, and the evaluative criteria. The next chapter will explore the findings.

Chapter Five: Findings

Three major themes were developed from the data: (1) living with ADHD; (2) exploring the accessibility of supports; and (3) exploring treatment. Each of these major themes were organized into several sub-themes.

Living with Attention-Deficit/Hyperactivity Disorder

The first theme describes different aspects that caregivers experienced raising a child diagnosed with ADHD. It includes the following subthemes: (a) the symptoms and their impacts; (b) exploring causes; (c) comorbidities and differential diagnoses; and (d) the strengths of ADHD.

The Symptoms and Their Impacts

Participants did not debate that ADHD exists. They noted several behaviors, including difficulties with following instructions and rules, sitting still, focusing, concentrating, controlling impulses, thinking flexibility, dealing with changes in plans, being more emotionally sensitive, being more sensitive to sensory stimuli, being easily distracted, and hyper-focusing. One participant also noted that her child seems to be more immature emotionally, as well as having "no concept of body space." Other words participants used to describe their children included "rambunctious" and "busy".

When their children are overwhelmed, participants described how their children will become very stubborn, have "epic tantrums," display "hands on" behavior, and get into often physical conflict with siblings. One participant described how her child handles being out in public:

> He is like a little spring, so he would do really well when he was out because he knew that was the expectation because we would pre-load him, but then he would come home

> and it was like 'whoa.' He would let it all go and he couldn't control it any longer. (Alice)

Participants indicated that their children lack coping skills. This participant's husband has a diagnosis of ADHD. She compared her husband's coping skills with those of her child to highlight that her child's behaviors are due to a lack of coping skills that she is in the process of learning:

> I know that as my husband's gotten older, he says he still struggles. He's still on medication but he is able to understand his responses. He is able to understand when he is triggered. Over the years, he has learned coping skills to get himself there. She hasn't. Her coping skill is to, for lack of a better word, lose her shit. (Caitlyn)

Three participants noted that difficulties started when their children entered school, and the final participant, whose child was not yet school age, reported that behaviors became a concern after a series of transitions which included moving to a new town, a new house, and a new daycare.

All participants noted several ways in which their children and their families are impacted by the aforementioned symptoms, including difficulties going into public like to grocery stores or restaurants, and potential family breakdown with parents separating. Their children's behaviors can bring up feelings of embarrassment in public and fears of being judged by people who do not understand what it is like raising a child diagnosed with ADHD, as this participant described:

> Most of the time she is pretty good when we go to public, but when she's triggered it's like you might as well talk to a wall. She will run up and down the aisles in the grocery store if we take her. She will touch everything and knock stuff over and knock into stuff.

> People are looking at you like, 'Control your child', and you're like, 'Oh my god. I want to crawl into a hole because you people are judging me and you know nothing about me.' I'm embarrassed because you see these other kids in a cart being quiet, and that's not her, and that will never be her. (Caitlyn)

Other participants added that they must "constantly nag" and provide frequent reminders to their children. All school age participants noted that their children had been bullied. Participants variously endorsed feelings of exhaustion and feeling "stuck in the trenches." One participant described it this way:

> It is mentally and emotionally exhausting. It is really hard to listen to your kid swear at you and throw things and know that this little person doesn't mean it and they're stuck in the moment, and through it all, we have to be the grown up. (Alice)

Siblings are also affected. One participant described how her child unintentionally hurts her younger sister sometimes because she has a lack of awareness of her body. Another participant described how a sibling had had enough: "My daughter was like, 'I'm going to go live with auntie. I don't want to live in this environment anymore'."

When someone is exhausted, it is difficult to regulate their responses to further stressors. This can lead to people lashing out or breaking in various ways. This participant described feeling guilty when she needs to ask her husband to step in for her:

> What could be a 15-minute getting ready for bed session turns into 45 minutes and usually ends up with me just dumping her in bed and saying, 'goodnight, I love you' because I'm done. I'm done. I don't think she is aware of how many buttons she can press on both my husband and I, but it has been to the point where I'm like, '[husband's name], you need to tag me out. I'm about to lose it. She's driving me crazy. You need to

> step in.' And then he'll be able to step it. But then it happens when she's like, 'I'm driving mommy crazy, aren't I?'. . . Then I feel bad because I know I am about to lose my mind and I don't want to yell at her because it's not really her fault. (Caitlyn)

This same participant added that the nature of her job increases her stress because she sees the worst-case scenario of where the things her child is struggling with may lead:

> It's exhausting sometimes and terrifying in others because she is very sensual without being aware that she is sensual and she doesn't have boundaries with people. So, in my line of work, I do unfortunately deal with those individuals who prey on children, and she is a prime target. So, for me, that literally scares the living shit out of me. (Caitlyn)

This participant further described the challenge of finding a balance when teaching her daughter to be cautious of strangers:

> We try to teach them the stranger danger without panicking them . . . I don't want her to be terrified that every single stranger out there is going to kidnap her, but I very much want both of my girls to be aware that there are people like that and they need to be cautious without being terrified. My sister errs on the side of caution and my poor niece is terrified of people she doesn't know. So, we don't want to be on that extreme, but we don't want to be lax either. We just want them to have a good awareness that there are good people and there are bad people . . . [striking that balance], it's awful. (Caitlyn)

Finally, participants described blaming themselves for their children's struggles, as this participant said: "I felt I had broken her somehow . . . by passing on genetics or whatever."

Exploring Causes

Participants discussed the things they think caused the behaviors they observe in their children. Three participants indicated that they believe genetic factors played a role. Of the four participants, one was diagnosed with ADHD herself, one suspected she has ADHD but was never formally diagnosed, and two had partners who were diagnosed. One participant endorsed a strong family history of diagnosed ADHD, and another mentioned suspected undiagnosed ADHD in her family.

Participants also indicated that there are neurological differences for children diagnosed with ADHD, as Alice explained: "Just like anyone's brain, sometimes it just works differently. And I think a little overstimulated. Yeah, I think that the brain just fires differently for ADHD kids." Alice also described several health issues for her child that began at birth. She reported prematurity, gastric issues, unilateral hearing loss from brain bleeds, and severe sleep apnea.

One participant brought up research that her husband had done on people with ADHD perhaps being "hunters in a farmer's world." She explained:

> What is interesting in a lot of his research that he has done and books that he has read is that ADHD seems to be more prevalent in not just Indigenous tribes but tribal people because it is a fight or flight. They are more in tune, they are easily distracted, they are hypersensitive, they are hyper focused . . . having those instincts of constantly being on the move . . . So, I don't know, maybe that's where part of my Indigenous background pulls in and maybe there is something to the research, and we've got that recessive gene that's come out in her. She's that hunter in a gatherer's world. (Caitlyn)

Participants also brought up home environments. Deidra talked about the factors that impact the behavior of other children at her son's school: "Just getting to school and having food

was a struggle, never mind learning something academic . . . [They were] flying off the wall." Brooklyn was very clear that the cause of her child's difficulties came from trauma and how that affected his brain development:

> Being from where I come from, I wasn't raised properly . . . I was pretty much on my own since I was 14. No one ever really taught me to be a parent, and on top of those things, when his dad passed away, I became really immersed into alcohol. That was my go-to and I was angry. So, the way I treated [child's name] was horrible. I neglected him and I was all about myself, my grieving. It was very selfish, and as a little boy, and as a grieving person, I didn't tend to his needs. So, I believe that he was lost himself and I think that led to the behavior. And as for the ADHD part, I think that the way his brain developed, having to fend for himself, it just developed differently. (Brooklyn)

Another participant noted that abusive behaviors from daycare staff seemed to be linked to an increase in the intensity of her child's behaviors:

> She was plunked into a new daycare, which unfortunately we have found was not the best place for her. It was actually quite abusive . . . They basically traumatized her over potty training. She was struggling with control, so the only way she could control was to hold in her bowel movements, to the point that she would get so constipated that we would end up at the hospital. (Caitlyn)

This participant explained that they would make her sit on the toilet until she went. If she did not go, they would put her down for a nap without letting her finish her lunch. Then, if she had an accident, the participant indicated that "the owner's take on that was, 'well, let her sit in it, she will learn next time'." Daycare staff would also not let this child have her toys if her pee was not visible in the toilet, prompting this child to refuse to drink water to make her pee more yellow.

The participant indicated that she also discovered that daycare staff were telling her daughter to not say anything to her parents because if she did, her parents would be mad at her. This participant also noted that there were several other transitions going on around the same time and that, ultimately, the cause is hard to determine:

> It was when she started at that daycare that she started acting out more. But then too, she had started there, and it was a new change, a new town, a new house. I was pregnant with my second. So, it was a lot of change being thrown at her. So, and then add in that stuff [with the daycare] and my husband figures that was just what triggered it. That was when the behaviors started. Would it have inevitably started? I'm sure. Would it have been later? I don't know. Would I have happened regardless? I don't know. (Caitlyn)

Comorbidities and Differential Diagnoses

The majority of participants described different ways in which they grappled with comorbidities and differential diagnoses. Two participants brought up that they thought that their child might have an anxiety disorder, one was diagnosed with an anxiety disorder by a pediatrician, and a third described her child as "anxiety ridden." Sensory sensitivities were also mentioned by one participant:

> She hates getting her feet wet in shoes. In the winter, she had run into the back yard for some reason and she had her winter boots on, and she sunk. As she was coming back to the pavement, you could hear her say, 'kay don't panic, kay don't panic, kay don't panic, kay don't panic,' because she had snow in her boots. (Caitlyn)

One child was also diagnosed with oppositional defiant disorder (ODD), but after describing how her child had been acting angry and aggressive after his school had been evacuated following threats made against it, this participant had this to say about the diagnosis:

> That night, he was angry over nothing. I finally just said to him, 'you need to tell me, what are you thinking? Because since Friday, you've been really angry and really aggressive, and you've been grumpy, and you've been moody. And you just need to tell me what's going through your head so I can help you.' And that's when he said, 'I don't want to die at school.' . . . So now, I really think, yes, there is ADHD, but I think that ODD piece and that anger piece may be more motivated by fear and anxiety. (Alice)

The three participants with school age children all endorsed learning difficulties for their children. One had been diagnosed by a psychologist with a specific learning disorder in mathematics, along with an overall intellectual ability that just barely fell above the cut off for an intellectual disability. This child had a very high ability to notice what was around him, but not the cognitive functions to process that information. The caregiver of this child explained that the psychologist had said that it was commonly seen in children who experienced trauma in their early life. Another participant indicated that her child had a "speech impediment."

Enjoy the Ride: The Strengths of ADHD

Participants identified several things that make their children unique and, in fact, will serve them well throughout their lives if they learn coping skills. For example, one participant indicated that her son "thinks outside the box." Other descriptors used included "smart," "phenomenal memory," "beautiful little mind," and "a psychologist's brain that can analyze people and situations."

This participant reminded parents to find joy in their children:

> I think that when you are raising a kid with ADHD, it is appreciating that sometimes the things that irritate you the most are also their biggest strengths. Just enjoy the ride and laugh . . . There have been a lot of times where we have sat down and literally cried, but

> there have also been a lot of times where we just had to laugh . . . Sometimes I think we get so caught up in being in the trenches with these kids that we forget to stop and enjoy the ride a little bit more with them. (Alice)

Participants all indicated that they hope that their children can build on these strengths to "be happy" and "live their best lives," including learning skills to cope with how their brain works so they can be successful. One participant expressed a hope for her child to enjoy school when she enters it and that she does not want her child labelled "the problem child," and another hoped that her son would be free from being discriminated against for his Indigenous identity. Two participants expressed wanting things to be different for their children than it was for them, including being free from shame about their Indigenous identity and to "not have the trauma that I've caused follow him."

Exploring the Accessibility of Supports

In the second theme, participants talked about different factors that impacted accessibility of supports and services, as well as recommendations they had to improve accessibility. Subthemes explore accessibility regarding (a) systems, (b) attitudes of individuals and society, (c) information, and (d) trauma, as well as (e) the role of advocacy in accessibility.

A Huge Disservice: Systems and Accessibility

Participants described encountering and accessing various services. These included schools, daycares, the Northern Health Assessment Network (NHAN), family doctors, pediatricians, the Prince George Native Friendship Centre (PGNFC), the Aboriginal Supported Child Development Program, Intersect Youth and Family Services, the Child Development Centre, and Venture Academy. One participant was on the waitlist for NHAN, had a pediatrician, and had accessed counselling at the Native Friendship Centre; the second was on the waitlist for

both NHAN and a pediatrician, had a psychiatrist, and had accessed both the Aboriginal Supported Child Development Program and the Child Development Centre; the third had received services from Intersect Youth and Family Services, where a psychological assessment had been conducted, and had attended Venture Academy in Kelowna; and the fourth had a pediatrician, had accessed counselling at the Native Friendship Centre, and was waiting for a psychoeducational assessment through the school district.

One participant identified several factors that increased the accessibility of services, specifically regarding school. She described how the approach her son's school takes is beneficial for her child. She indicated that "they allow him what he needs to be successful", including standing, sitting in a corner without distractions, sitting in the hallway, going to another space to work, and having body breaks. This participant further explained that her son's school gives him choices, "My son needs that. He needs to feel like he has some power, he has control, and he's in charge," as well as showing him respect:

> His school, they've always worked with him. . . the respect, and I think he needs to have that respect shown to him. If you don't respect him, he won't respect you . . . I know in any other school, he would've been suspended, he would've been the kid sent down to work in the principal's office, he would be that kid out in the hallway, he would be that one who is speaking rudely to a teacher. (Alice)

On the other hand, participants consistently identified barriers to accessibility. One mentioned by the majority was waitlists in the community:

> The waitlists are insanely long. They are crazy. I understand they take priority cases, but still, there are a ton of kids . . . We've talked to [psychiatrist] who basically said, if she

> doesn't get diagnosed prior to going to school, it will be maybe by the time that she is 12 before she even gets it, and by then it's too late. (Caitlyn)
>
> I think that is the hard part. Yeah, there are services for kids with ADHD. The Native Friendship Centre, I think they are up to a six-month waitlist. Now, Intersect, a year if not more. That's not right. That's a huge disservice to our kids and it's a huge disservice to our families who are raising ADHD kids. It shouldn't be that way . . . it leaves us as parents trying to figure it out on our own. And it's hit or miss. And we're guessing and we're doubting our decisions on if this is the best choice. (Alice)

Another participant indicated that her child had first been identified as potentially having a learning disability when he was in Grade 3. She was told that a psychoeducational assessment would be done in Grade 7, and despite a letter from his pediatrician going to the school, he is in Grade 9 this year without an assessment.

One participant noted that "we can't do anything unless we get a diagnosis" and that this, combined with the long waitlists, "stalls us for a lot of other options." This participant further noted that doctors will not diagnose ADHD before 5 years old, which made her feel that they could not access resources for early intervention. She explained: "We want to know before she gets to school because once she gets to school, she is going to fall through the cracks."

Some families can circumvent waitlists by paying for assessments privately, but as one participant noted, this is not possible for many Indigenous families:

> Even as a working parent with access to resources, I find it's not accessible. We were looking at paying for the assessment ourselves. We don't have financial barriers, but how many families have an extra $3000 kicking around for assessments for their kids? Not a lot. (Alice)

Another participant further noted that not only is there a lack of resources that lead to long waitlists, but that many services are only for serious cases, such as Intersect Youth and Family Services. On top of this, the hours that services are available are not accessible for working parents.

Participants described trying to get services for their children as "frustrating" and an "uphill battle." One described how it is easy to lose hope and become disheartened: "If you have doors being closed, one after the other, it's kind of like, why keep knocking?"

Two participants identified that being Aboriginal meant that they had more options for resources. However, one of them pointed out that "I don't know if that means they [school] always give him support, but there is more available," and the other strongly expressed that she believes everyone should have access to resources, no matter how they identify:

> I don't see race as being something that we should promote more resources for or not. If a person is suffering with ADHD or mental health issues or something like that, I personally believe that they should have access all the way across the board. Preference shouldn't be given to somebody because they can check a ticky box. (Caitlyn)

Therefore, it was recommended that there be therapists in schools to mitigate the pressure on working parents, as well as more services available after hours. Another participant indicated that parents should have more access to healthcare professionals in order to assist with diagnosis to support early intervention, and another urged parents to seek psychological testing so they can get support for their children in school.

Brushed Aside: Attitudes and Accessibility

Individual attitudes and beliefs of professionals, people in public, and friends and family members also impact accessibility of services for families. Some of these factors can increase

accessibility. Two participants indicated that individual daycare workers with knowledge about ADHD because of their own personal experiences were important in them figuring out how to help their children. Pediatricians also increased accessibility with how they approached supporting families. Two participants indicated that they felt that their pediatricians listened to their concerns and, in particular, listened to their children:

> I feel like she really listened. She was actually really good. She was just really calm, she was nice, she listened to us. She would talk to [child's name] and even though he was so pissed off that he would have to be at a pediatrician, she would just talk to him like a human being. She really rooted for him. (Brooklyn)
>
> It did seem like the pediatrician was listening to what we had to say. She wasn't dismissing [child's name], like 'oh, what do you know about it, you are just a kid.' It's him it's happening to. (Deidra)

However, participants more often identified different ways in which individual attitudes and beliefs decreased accessibility of services for them and their families. One participant described how getting unsolicited advice from misinformed people, including family and friends, about ways to support their child affected her and her husband:

> I think a lot of times, temporarily, we would question ourselves: 'is this the right thing to do?' I think especially my husband struggled a lot more with that because his family is very natural, holistic, kind of anti-medicine and that type of thing. They go the route of holistic doctors and that type of thing so it was a bigger struggle for my husband because he would get a lot more comments from his mom or his sister . . . So, it would make him doubt a little bit more. (Alice)

Another participant described how individual doctors would make assumptions: “I’ve run into a couple doctors who figure just because we’re pushing the ADHD that we want her medicated, which is not the case.” This participant felt very dismissed by her family doctor and also pointed out that how much power doctors hold in the referral pathway can be a problem: “Your doctor has got to be the one to put the referrals in and if it dies with them, then you’re beat.” This participant’s doctor ended up retiring, and they got a new younger family doctor: “I am just thankful that we swapped doctors because I’m not sure that our old doctor would have put that through [psychiatry referral], regardless of what they [the Child Development Centre] said.” Another participant found that her family seemed to receive less support from their pediatrician when they were not wanting medications, and a third expressed feeling that concerns about issues other than ADHD, such as anxiety, were “brushed aside” by the pediatrician.

Individual attitudes and beliefs also decreased accessibility of supports in school. For example, a lack of awareness from individual teachers was mentioned:

> The teachers are all individual. His last teacher was like, ‘I don’t think he has any learning issues; he just doesn’t get his work done. He just needs to buckle down.’ That kind of attitude. I’ve been trying to get him to buckle down. I have to sit and watch him do his work. It’s painful. (Deidra)

This was described at an administrative level as well. One participant indicated that “not a lot of people worked well with that principal” and described having to go “toe-to-toe” with her to get her child’s needs met.

Another participant mentioned that she does not think ADHD is taken seriously by professionals:

> Sometimes I wonder if they think maybe it's a behavioral or a parenting thing. Sometimes I wonder, even within the community, we still have that where it's not as big of an issue, or it's 'just' ADHD. (Deidra)

As such, several participants voiced a desire for people to have a more complete understanding of what it is like raising a child with ADHD:

> When you have a kid with ADHD, it's so much more than ADHD. It impacts school, it impacts home, it impacts your relationships. (Deidra)
>
> It's frustrating, it's hard, it's heartbreaking, and it's rewarding all at the same time. I love her to pieces and she's brilliant, she's smart, she has a beautiful little mind, but oh my god can that girl push my buttons. (Caitlyn)

Moreover, participants described how their Indigenous identity impacted them. One participant described a fear of being judged because of her Indigenous identity. She further explained that she always makes sure that her son knows where bruises he has from the sports he participates in come from:

> It is the reality where people have our kids under a different microscope and they see that and would assume that we're harming him, and if he doesn't know where it came from, then it could get us called into the Ministry. And I know that as a parent. So that's one thing that I've always been very aware of as an Indigenous person, is that we are under a different microscope. (Alice)

This participant further elucidated that she feels like she also has to prove herself as a parent:

> I have to prove myself different as a parent, as a mom . . . Making sure that I am present for every conference or for every open house and anything like that because I don't want anyone to look at me and be like, 'oh, that mother of the Indigenous kid is not here.' And

> that's my feeling. It's not the feeling that is put on me, but I feel that when you are Indigenous, the bar is here for everyone, but I feel like as Indigenous people, we have to go a little bit higher, because if we just come to where everyone else is, it's not good enough. You've got to go a little bit harder, you have to prove yourself differently in the workforce and at school and as a friend, as a mother and everything. I just feel like, as an Indigenous person, we have to work harder for the same recognition that other parents get. (Alice)

Another participant described feeling like her son was blamed for a situation in school because he was the only Indigenous student involved. As she noted, "racism happens all the time and all those teachers were white." Another participant also described experiencing subtle racism:

> It's just the way our system is still in Canada. There is a lot of judgement still. Still so much racism, and I think it is racism that people don't even realize is racism. Like people are talking, 'oh, you are Indigenous? You have a career? You've gone to school?' You would never say that to the person sitting next to me, and yet you have that assumption that because I am Indigenous, it is amazing that I completed grade 12 and went on to college and I have a job and I have a family. Basically, what they are saying, I fell, is that 'oh, you you're not a drunk.' It's implied when they say that. 'Oh, do both of your children come from the same father?' Who asks that? Why would you ask me that? (Alice)

Participants asked for professionals to "listen to what the kids and parents have to say" as well as to help with options outside of medications. Regarding concerns expressed by one participant about anxiety being dismissed, she noted that simple acknowledgement would go a long way:

> It would just be easier, even if he acknowledged to me, 'yeah, it sounds like he has a more anxious personality.' I'm not necessarily looking for a medication to deal with that, but if it's there, I just want it acknowledged. (Alice)

Another participant encouraged service providers to:

> Be blunt with the parents. Don't use a whole lot of medical jargon. Don't try to pussyfoot around the situation. I don't want things sugar coated. I want to know what the challenges are going to be. I want to know what their experience is dealing with children like this. I am also not that parent who believes my child is an angel . . . I want to know the good, the bad, and the ugly because that is the only way (a) we are going to be able to correct it and (b) we are going to come up with a game plan. . . I need to know that stuff whether they think that is going to offend me or not. I need to know that, and I need to be able to work with the teachers and with the doctors. (Caitlyn)

Where to Go? Accessibility of Information

The various formal supports that are available for families of children diagnosed with ADHD are only useful if caregivers know they exist. Participants talked about different ways in which information is shared to connect them with services, as well as barriers to knowing this information. One participant indicated that she learned more by connecting with friends and other parents of children diagnosed with ADHD than she did any professional:

> It means a lot to connect with other people and go, 'okay, I am not the only one dealing with this, pulling my hair out like, oh my god, what am I supposed to do?' I think that is usually the most helpful, to be in contact with other people who are going through the same stuff and being able to throw out suggestions about what works for them and other stuff. (Deidra)

Others indicated that they learned crucial information from daycare workers. In fact, one participant explained that it was just by chance that their child was identified as needing extra support by a case worker who was working with another child in their daycare. In this way, they were able to be connected to the Aboriginal Supported Child Development Program.

Another participant indicated that she and her husband did their own research, and explained that this was important for them in their process of sifting through the opinions and judgements of others and coming to their own conclusions:

> A lot of people were like, 'well, if you medicate him, he is going to end up addicted to drugs. Whereas, if you do the research, it actually shows the opposite. If they're not medicated, then there's an increased risk of drug and alcohol abuse . . . Both my husband and I research things really well before we made choices and decisions for medications, and I was really glad because my husband and I said that if we didn't have that information and someone said 'he is going to be addicted to drugs later on' it would be like 'oh, I am not going to do that then' . . . We were happy that we did our research. (Alice)

Participants were also able to draw on their own or their partner's experience being diagnosed with ADHD when trying to make sense of the behaviors they were seeing in their children and making decisions about treatment, as these participants explained:

> It was my husband who noticed, I would say at probably about 2 and a half, 3ish. He started just noticing a few behaviors that he remembers displaying when he was a kid. (Caitlyn)

> I was put on Ritalin for my ADHD and so, going back, people were like, 'oh, you know, it is going to change your personality' and I think I turned out fairly normal, so I had that to go on as well. (Alice)

Another source of information was participants' places of employment. Skills and knowledge gained at work were important for several participants supporting their children at home:

> I am glad that I have the job that I have because it also has given a lot of skills that I receive at work also translate right to what is going on in our home . . . Sometimes I will take workshops because maybe it applies more to my life. But it was a way for me to get what I needed for him. (Alice)
>
> I am thankful that I have the resources even through my work. I am able to use my colleagues to pick their brains. (Caitlyn)

Overall, however, two participants expressed feeling like they had "managed everything on our own" and that "I have to figure out [things] on my own." Another identified her main challenge as knowing "where to go?" Participants endorsed a lack of knowledge about what resources and services are available for them, as well as what their rights are. One participant explained that schools will often put children with behavior problems on reduced schedules. She compared her situation, in which her case worker had been able to tell her that schools are not allowed to do this, to one of her clients, who did not have that information:

> There is not enough information available to parents on how the school system even works. I had [a client] whose son was only allowed to go to school for two hours a day because he was ADHD and hyperactive and couldn't sit still. And when we were sitting

> with [case worker], I brought that up. No, schools are not allowed to do that. But, I mean, I wouldn't have known that if I hadn't have asked the question. (Caitlyn)

Another participant pointed out how even a seemingly small piece of knowledge can shift perspectives and make a big difference in supporting caregivers as they raise their children:

> I had read an article on ADHD and executive functioning. I wish that somebody had told me that three years ago about executive functioning and what it is. It was very clear, you have a 9-year-old age wise, their executive functioning is more of a 6-year-old . . . it was mind blowing to me . . . when I stopped and started approaching him more from that executive functioning age, it changed our world. (Alice)

As such, two participants recommended having information about ADHD and steps for families to take regarding pursuing assessment in a centralized location, such as on a website or in a pamphlet made available in daycares and doctors' offices.

It was too Much on my Shoulders: Trauma and Accessibility

Participants shared how experiences with trauma and the adverse childhood experiences their children were going through impacted their ability to access services. They identified various adverse experiences, such as parents being diagnosed with anxiety and depression, possible undiagnosed ADHD, parental history of drug and alcohol abuse, emotional neglect, parental separation, and the death of one parent.

These adverse experiences impacted participants in several different ways. One participant explained that when a parent is trying to cope with trauma, it is difficult to learn from any services they may be accessing:

> I was young and fuzzy headed from drinking all the time, so I wasn't there to be able to cope or learn or really take in the coping. I remember, they did this program, Stop Now

> and Plan, or something like that. I think that was what it was called. It was a bunch of parents going in with kids with behavioral stuff and how were we going to deal with it and have a better relationship. Well, I was so engulphed in my alcoholism and men and other things rather than fixing my family. I was still so angry that I never grasped onto those things. And it was for Indigenous families, this program. So, the challenges were that I wasn't just caring enough about life to even bother having people help. I felt alone, so I just gave up and I was like, 'what's the point?' It was too much on my shoulders dealing with my own trauma plus dealing with the trauma that I was causing. (Brooklyn)

Participants also described different ways that their own coping impacted their ability to access services. One participant indicated that she was raised in an environment where she always had to be productive:

> I wish I wasn't so rushed. I grew up with this 'you need to be productive and doing something, you can't just sit there not doing anything.' So, I am always doing stuff and I'm just always stressed . . . I have a hard time slowing down. (Deidra)

This meant that this participant did not pursue many of the resources available to her and her child because she was too exhausted. It also impacted her relationship with her child: "Maybe he feels that I am not available to him, or that I don't care about him as much as I do because I'm always doing stuff."

Due to growing up in environments where abuse was present, one participant explained that she had no support from her family when trying to raise her child:

> I was alone. My family didn't want to deal with it. They were never really there growing up because I was in foster care, then all by myself. So, they were never there to support me, so I was all alone. (Brooklyn)

Trauma and adverse experiences also impacted families' experiences at school. One participant indicated that she and her son had had a difficult situation with her son's school. She described it as "a horrible part of our life." Her son was just above the cut off for an intellectual disability and had been led by other students in his school to make certain comments to a female student. The school responded punitively, sending him home and conducting a threat assessment:

> He would get kicked out and I didn't understand why. It was just such a horrible time. It was horrible. The things that were said about him were horrible and I knew that he, in his heart, he didn't mean it. There were accusations and he was like, 'what? I didn't mean that.' And in my heart, I knew my son wasn't meaning to be the way he was, but he was hurt. He was hurting. (Brooklyn)

This participant explained that the school "made him out like a predator" and "made him feel like he was the shittiest thing in the whole world, and he's not. He was troubled and that was as far as that went."

Three participants pointed out that schools will often send children home or put them on half days because of behavior problems, instead of supporting them in the school. They pointed out that these kinds of reactions from the school inadvertently cause compounding trauma. As the participant above said: "I'll never forget him sitting there and like 'am I a bad person?' They did that to him." This participant had also sent her son out of the community to cope with the situation with the school, which led to further trauma:

> I sent him away to my cousin's and that caused more trauma because she comes from the same family on my dad's side. All of my aunts and uncles are alcoholics and they did not deal with the residential school stuff very well. We are a product of them, so I ended up

> sending my son to a cousin who had more problems than I did, and I didn't realize that, and she caused way more trauma. (Brooklyn)

Another participant noted how sending children home may impact them:

> That puts a label on the kid. Because now the kid is being told that she can't handle being in school so she can only be there for a few hours because she is such a problem. It's rejection. It messes with their self-esteem, their self-confidence. Teenagers struggle with self-confidence on the best of days. So you have one who has routinely been told that they are an issue, they are a problem, and are being put in special classes all throughout elementary school What do you think is going to happen when they become teenagers? They gravitate towards the rest of the kids who feel like that and the next thing you know you are dealing with drugs and all that fun stuff. (Caitlyn)

Participants also shared how their own trauma experiences motivated them to make it better for their children. One participant talked about how she was taught to be ashamed of her Indigenous identity growing up, and how this motivated her to want better for her children:

> My mom never told anyone that we were Indigenous growing up. I think there was a lot of shame. My granny went to residential school . . . I hope it's going to be different for my kids . . . My kids are learning about their culture and their background, and they're not embarrassed to say who they are . . . They know who they are. They know their roots . . . So, I hope that it'll be different because we don't have that shame attached. (Alice)

Another participant described the growth that she went through and how it has changed her relationship with her child:

> I've realized that just because I was hurt before in my life doesn't give me the right to keep going with negative mind thoughts, negative ways of being . . . Realizing that my

> son is a blessing and that we have a chance now, it's never too late. So, I've switched my ways of being. Sometimes I fall back into my old ways . . . it's hard to take away trauma. But I catch myself . . . If I do mess up with the way I've dealt with something, I walk to him [son] about it and I apologize. I own up to it. (Brooklyn)

This participant beseeched professionals to be "thoroughly educated about issues" and to "treat people with compassion and understanding and not pinpoint everybody." By "pinpoint," this participant explained that she meant racially profiling Aboriginal children. Moreover, she said that "they [professionals] need to understand very thoroughly that parents of these children are also probably going through that shit too."

We Are Our Children's Voices: The Squeaky Wheel

"The squeaky wheel gets the grease" is an American proverb meaning that the most noticeable problem gets the attention. In this case, we are talking about advocacy and the level of disturbance children's behaviors cause within the classroom.

All participants talked about the importance of advocacy, whether by directly standing "toe-to-toe" with schools, or through omission by giving examples of what happens when advocacy does not happen.

Some examples of advocacy that participants gave were phoning every month to follow up with their child's status on the waitlist at the Northern Health Assessment Network (NHAN), demanding to be referred to NHAN again after their first referral was rejected, going to the Child Development Centre after their family doctor dismissed their concerns about potential ADHD, talking to the resource teacher at their child's school to set up appropriate supports, and refusing to allow the school put their child on half days.

One participant highlighted what can happen if families do not advocate for their children:

> It breaks my heart, because I know there's other families who can't do this [advocate] for themselves. They don't have that advocacy skill or the confidence to say, 'no, no, no, you are going to find a way to make this work.' And so, 'oh, you want him to go one hour a week to school? Okay." But that's not what they want. (Alice)

Another participant noted that her child, while still struggling, was not doing it in such a way as to disturb the class and so did not get the extra support that he needed:

> Because he is not a bother in the classroom, because there are other kids with issues. In grade school, he was on the list, but he wasn't the squeaky wheel. He always got looked over for that kind of help. (Deidra)

The two participants who indicated that they strongly advocated for their children, in one participant's case feeling like she had to be "a real bitch to get my voice heard," were able to get connected to a psychiatrist in one case, and both were on the waitlist for NHAN before 6 years of age. In another participant's case, her child's behaviors were so severe that the family was connected to Intersect Youth and Family Services where the clinician advocated to get a psychological assessment done. In the last case, the participant trusted the school and did not push for assessment in her child's early years. He was put on a list for a psychoeducational assessment in the school district in elementary school and is still on the list in high school. Every participant endorsed some degree of exhaustion connected to having to advocate for their child. As this participant said:

> Why have I had to fight this hard? Why have I had to fight to get him on an assessment list? To have it acknowledged that his brain is different? I shouldn't have to work this hard to get this kid services. (Alice)

All participants wanted to give advice to other parents and caregivers encouraging them to advocate for their children. One participant told other parents to "stand up more" for their children than she had been able to. Another participant said that parents should trust their gut:

> We need to be able to trust our gut. If our gut says something, we need to follow through with it. Because if we don't, nobody will. So that is probably the only advice. Be tenacious. Be a Pitbull if you have to . . . People are going to be dismissive and people are going to try to push you off. And I'm like, well it's a good thing that I am annoying. (Caitlyn)

This participant also encouraged other caregivers to be their children's voices:

> Don't take no for an answer. Always seek a second opinion. And, to sound like a hippie, fight the system. But really, we are our children's voices. They don't have them, we have to be them and we have to be tenacious and we have to be annoying and we need to be in people's faces about this because if we don't do it for them, they are going to slip through the cracks. (Caitlyn)

Another participant added that if parents and caregivers cannot advocate for themselves, find someone who can:

> Advocate, advocate, advocate. If one door closes, go to another door, and don't stop until you are happy with the services you are receiving and the answers you are receiving . . . and if you don't have a voice, then find someone who can help you advocate for your child. (Alice)

Overall, not giving up was identified by three participants as a strength they have as parents. As one participant said, “I’m not giving up on him.”

Exploring Treatment

The final theme describes participants’ experiences with different treatment options for their children and includes the following subthemes: (a) behavioral interventions, (b) medications, and (c) navigating their children’s right to self-determination regarding treatment decisions.

Finding What Works for You: Behavioral Interventions

Participants identified several strategies that they had tried using to support their children. These included having a sensory box at daycare; establishing routines; giving their children reminders of tasks verbally, in writing, and via text; frontloading transitions; using timers; tagging out with their partners when they were losing their patience; modelling coping skills; rewards charts; limiting distractions during homework time; teaching them problem-solving skills; and using emotion coaching strategies to help their children deal with big emotions. One participant tried dietary changes and another was considering doing so. Another participant had tried CBD oil and found that this made a big difference for her child to help him sleep and cope with anxiety.

Participants described their approach to raising their children considering their neurological differences in various ways:

> She has so many amazing qualities about her. She’s compassionate, she’s caring, she’s sweet. But at the same time, she can also lack empathy and impulse control, quick to temper, has no boundaries. So, we are trying to strike a balance between nurturing the amazing qualities while trying to help her deal with the challenging qualities. (Caitlyn)

> Talking about discipline or removing stuff from him only makes it worse . . . We try to be very consistent. If it was a reasonable request and if it was logical then you would have to do it . . . We didn't want him to be able to run over us and we felt really strong as parents . . . Sometimes we would make a decision and go 'kay, that wasn't reasonable . . . so, we might loosen the reins but then talk about it later. (Alice)

In addition, participants talked about not wanting to make their children feel shame, as this participant said, "we are trying to normalize it because I don't want her to think that because she has the label ADHD, that is a bad thing." (Caitlyn)

One participant had this to say to other parents and caregivers:

> Try not to be too hard on yourself or your kid. Figure out what works for you guys. It is not a one size fits all solution. Like [child's name] isn't very hyperactive by he doesn't have a very good ability to focus on stuff. So, it's figuring out from whatever sources you can to help them be their best selves. (Deidra)

We are not for it, we are not Against it: Medications

Three participants had tried medications for their children and the last was considering medication. Only one participant's child was taking medication at the time interviews took place.

Participants described a mental struggle for themselves about whether to seek medications for their children. They worried about side effects and about more medications being added to deal with side effects. One participant used the words "snowball" and "trap" to describe this process:

> I know it can build up. Once you start on one medication, there is the side effects. I could see how it could snowball and I didn't want him to have to be dependent on them . . . you

> have to treat the side effects . . . It is kind of a bit of a trap. Once you start, it is hard to stop. (Deidra)

Another participant used the word "overmedicated" in a similar fashion and defined it as following:

> For me, overmedicated is: we have one issue, we're dealing with that; but now we have created another issue so we are going to add another medication; oh, but now we have this other issue and so we are going to add another medication. (Alice)

Two participants of the three who had experience with their children being on medications indicated that their children had told them that they didn't like the way the medications made them feel. Participants further described fears of their children becoming "zombies" or of their personality becoming "muted."

However, participants also noted that medications have many benefits. One participant indicated that "when we did try the medication, it totally changed things and he was able to focus." Moreover, another participant explained that, despite her concerns, the medications did not change her son but instead helped him be more himself:

> I think, overall, he's still the same kid he was. He's just a bit calmer, he's not as impulsive and that type of thing. He's still the same spunky kid he was. I was afraid that when we put him on medication that, because you hear so much 'oh, they're gonna be a zombie" and that type of thing. Where my experience is, he's just himself. He's just a little bit calmer, he's just a little bit less impulsive, but he's still the same great kid he was prior to medication, and he's happier. He's happier with himself and our home is able to function better. (Alice)

Two participants also noted that their children had verbalized how medications are helpful for them. For example, “He is quite a bright kid and he would say, ‘if I don’t take my medication, I’m an asshole.’”

There was only one participant who said that she does not agree with giving medications to her child for ADHD. This participant’s child was older and they had tried medications before. As she explained, the side effects were worse than what the medications were trying to help:

> He was a zombie. He was not himself and his eyes would be bulging out of his head. He told me straight that he doesn’t feel good, his stomach would hurt, he wouldn’t eat . . . It was horrible . . . It made him concentrate a little too hard by the way. I brought him to the hospital once because he was concentrating so bad, on bad things. (Brooklyn)

Participants noted that when the behavioral interventions were not working or when their children’s mental health was being impacted, that was the threshold at which they would consider medication for their children. As one participant put it:

> He would lie in bed crying, ‘I don’t know why I’m doing this. I’m not a good boy.’ Then one day he said to me, ‘I don’t want to live this life anymore,’ and he was 6 years old. And then I was like, that’s it. This is impacting his mental health and his self-esteem, so there was no doubt in my mind or my husband’s that it was time to look at medication because the impacts were so bad on him. (Alice)

Another participant pointed out that she and her partner would put their own opinions aside for what is best for their child:

> We are not for it, we are not against it. It is just whatever is best for her. If it ends up being medication is the best for her, our personal feelings aside, we do what’s best for her. (Caitlyn)

One of the participants worked in the school system and she noted that it seems like Indigenous children are more likely to be medicated according to her observations. She had the following speculation:

> I sometimes wonder if it is schools pushing, 'oh there's behaviors, there's behavior.' And maybe not acknowledging past trauma, financial barriers and things that may be happening in the family . . . Kids don't fit in the box. You can't make a circle fit in a square. So now we're gonna try to make your kid a square so that we can fit them in our square box. (Alice)

Another participant noted that, "I guess it is like putting a leash or a muzzle on someone's natural personality or natural way of being."

At What Point do you Let the Child Have a Say? Navigating Their Child's Self-Determination

Three participants with children who were school age talked about trying to balance their children's need for a voice with what might be best for their long-term mental health.

One participant pointed out that she believes it is important to "stop and listen to his voice because ultimately there is going to be a time where he is going to choose to medicate or not medicate." Another described trying to support her adolescent son who was struggling in school. She indicated that he would not attend counselling consistently and that he did not want to take medications despite his mother observing that they seemed to help him in school. She noted:

> My conundrum is at what point do you let the child have a say? . . . I wouldn't have had a say [when I was a kid] about whether I was on it or off it. But I've offered [child's name] a say. It's his body, right? It's his life and stuff. (Deidra)

Another participant, who had indicated that she did not agree with giving her child medication, expressed support for her child's decision when he indicated that he wanted to try again:

> Recently, [child's name] on his own has said, 'I would like to go in to maybe see if I can get some pills.' And that is just for school, like concentration . . . He does know that it's harder for him to concentrate. (Brooklyn)

Summary

This chapter described the findings of the study to answer the following research question: "What are the experiences of Aboriginal peoples in Northern BC acting as caregivers to Aboriginal children diagnosed with ADHD?" There were three themes developed from the data, each with several sub-themes. The first theme described the experience of living with a child diagnosed with ADHD, including the impacts of symptoms, contemplating causes, dealing with questions of comorbidities and differential diagnoses, and recognizing the strengths of their children. The second theme talked about the accessibility of supports, including on a systems level, regarding the attitudes of individuals, accessing information, how trauma impacts accessibility, and the role of advocacy in accessibility. Finally, the third theme explored treatment, including behavioral interventions tried by caregivers, their experience with medications, and the considerations of including their children's opinions in treatment.

Chapter Six: Discussion

This research focused on exploring the experiences of Aboriginal people acting as caregivers to Aboriginal children diagnosed with ADHD in Northern BC. This chapter will discuss the findings in four sections. First, the findings will be situated in the context of the existing literature. Second, the burden of responsibility will be critically considered in the context of anti-oppressive principles and allyship. Third, caregivers' experiences regarding vicarious trauma will be expounded upon. Finally, the etiology of ADHD will be explored. The latter three sections will collectively discuss what this research adds to the literature, namely, a discussion on trauma.

The Existing Literature

The findings of this study are largely consistent with other qualitative research with caregivers of children diagnosed with ADHD, both Indigenous and non-Indigenous, including in descriptions of symptom presentation (Loh et al., 2017), impacts on family and caregivers (Corcoran et al., 2017a; Cronin, 2004; Kildea et al., 2011; Leitch et al., 2019; Mofokeng & van der Wath, 2017), self-blame for their children's struggles (Araujo et al., 2017), the challenge of balancing the benefits and costs of medications (Corcoran et al., 2017b; Hansen & Hansen, 2006), lack of information regarding the referral process (Jimenez et al., 2012), the challenge of long waitlists (French et al., 2020; Loh et al., 2017), and the need to be a strong advocate in order to get referred for services (French et al., 2020). Quantitative research also demonstrates higher parental stress for parents of children diagnosed with ADHD than parents of children without neurodevelopmental disorders (Craig et al., 2016).

There was some variation in the findings of this study when compared to existing literature, including when discussing the nature of ADHD and regarding experiences with

medical professionals. Participants in this study largely described ADHD in genetic and neurological terms. This is in contrast to research done with Indigenous peoples in Australia who identified the cause of their children's behavior as being related to non-traditional diets high in preservatives, sugar, and additives, as well as a lack of attachment between caregivers and children (Loh et al., 2017). Relatedly, participants did not talk about the cultural appropriateness of services, as has been identified in other studies with Indigenous peoples (Loh et al., 2017). This could be because the participants in this study were urban Aboriginal and had all received some level of post-secondary education, which may have made them more familiar with Western approaches. One participant also mentioned the theory that people diagnosed with ADHD are "hunters in a farmer's world" that her husband had come across and that she gave credence to. Indeed, this is a theory that comes out of evolutionary psychology. It posits that the behaviors associated with ADHD were once adaptive when we lived in hunter-gatherer societies, and that as we shifted to permanent settlements, human evolution could not keep up (Dein, 2015).

Regarding experiences with medical professionals, participants largely described feeling listened to by pediatricians but also reported feeling dismissed by family doctors, having their concerns about difficulties other than ADHD brushed aside, not receiving support when not pursuing pharmaceutical intervention, and being faced with assumptions that they just wanted medications. Indeed, research has found that physicians will prescribe medications to children diagnosed with ADHD up to 100% of the time (H. W. Harris et al., 2017). Finally, participants did not mention thinking that their medical professional lacked information about ADHD, something which has been identified elsewhere (French et al., 2020).

The Burden of Responsibility

Participants described several ways that intergenerational trauma impacted them and their families, including a historically felt sense of shame of their Aboriginal identity, how they felt they were held to different standards because of their Aboriginal identity, and how service providers did not understand that children's behaviors were motivated by intergenerational and complex trauma, as well as not understanding that parents were also likely dealing with the effects of trauma. In Canada, Aboriginal children are overrepresented in child protection (Barker et al., 2014; Ellenbogen et al., 2013; Sinha et al., 2013; Sinha et al., 2011; Sinha & Wray, 2015), among people living in poverty (Beedie et al., 2019), and in the criminal justice system (Correctional Services Program, 2016; Malakieh, 2019). Youth themselves have attributed overrepresentation to the impact of residential schools and colonialism which led to disconnection from culture and tradition and the destruction of Indigenous families, as well as racism and stereotypes from authorities (Cesaroni et al., 2018). Quantitative research has consistently found that having a history of familial residential school attendance is detrimental to mental health and physical health (Elias et al., 2012; Gone et al., 2019; Hacket et al., 2016; Kaspar, 2014).

In the literature on allyship, it is clear that the burden of responsibility should not be placed on marginalized and oppressed groups to stand up to racism and discrimination. Bishop (2015) gives a list of guidelines when working to become an ally, including "try to speak up first. Do not wait for a member of the oppressed group to point it out" (pp. 95-96). However, participants in this study described having to manage largely on their own and having to be strong advocates for their children. In other words, the responsibility for addressing oppression fell to them. Moreover, anti-oppressive practice principles include deconstructing the medical

model with families (Larson, 2008), as well as acknowledging the social, cultural, and historical context of families seeking services, including an analysis of power; and recognizing that knowledge is socially constructed (Qwul'sih'yah'maht & Kundouqk, 2009). These principles are arguably not currently present in a meaningful way in practice to support Aboriginal families with children who have been diagnosed with ADHD.

Aboriginal caregivers held this burden in two ways. First, most participants in this study noticed challenges arise when their children went to school, which is reflected in the literature (Gwernan-Jones et al., 2015). One participant in this study talked about the school environment being a square box and children with ADHD being circles; the latter cannot fit into the former, yet that is what the current standard for intervention encourages with medical intervention. Psychologist Peter Gray theorizes that the decline of children's free play with other children, in part because of increased time in and importance given to formal schooling, has contributed to the rising psychopathology among children and youth (Gray, 2011), and research has found links between play and emotional skills, social competence, and self-regulation (Stgeorge & Freeman, 2017), as well as executive functions (Coelho et al., 2020). This suggests that our current conceptualization of formal schooling may impact the presentation of symptoms. Further, it suggests that it may not be appropriate for certain students. Indeed, participants spoke about how they feared their children would drop out of school, or of how their children had expressed a desire to drop out. Aboriginal youth have identified several factors important for success in school, including counselling and support in school, having Aboriginal teachers, including engaging curriculum that recognizes different learning styles, trusting relationships with teachers who provide emotional support (Bazylak, 2002). Unfortunately, this arguably does not often happen for many Aboriginal students. According to Census data from 2016, 20.1% of Aboriginal

men had less than a high school diploma and 15.9% of women, compared to only 8.5% of non-Aboriginal Canadian born men aged 25 to 34 and 4.9% of women (Uppal, 2017). Moreover, consistent with research with people of color in the United States (Blum, 2011), participants in this study noted that the school may pressure families to put their children on medications and that this may be motivated by Indigenous identity. In fact, research with African American parents and white teachers in the United States found that white teachers with more negative racial attitudes rated African American children higher on ADHD behaviors than white teachers with less negative racial attitudes (Kang & Harvey, 2020). This suggests that Aboriginal caregivers may feel pressured to try medications based on their Aboriginal identity and not on symptomology. Instead of challenging the structure of the education system, Aboriginal children are expected to change their behavior using behavioral and medical interventions to fit into the current system. In this study, one participant described how effective it can be when the established way of doing this is challenged. She explained how the approach her son's school takes gives him choice, control, and respect, and how this keeps him engaged. Choice and control have been identified as important trauma-informed principles (TIP Project Team, 2013).

Second, participants in this study arguably illustrated that if they did not fight for resources, they often did not get them. Moreover, they felt that they were largely left on their own to manage. When talking about ways to advocate and resist barriers in the system, Gwernan-Jones et al. (2015) noted that options for resistance, such as volunteering for school boards or paying private tuition, are not equally distributed among families of children diagnosed with ADHD due to financial, intellectual, and social barriers. As a result, parents without the resources to advocate for their children may find themselves in situations where trauma is compounded, as illustrated in this study. For example, children are sent home from school due to

behavioral issues and they feel like they are bad kids. One participant indicated that she had tried to resist the school's treatment of her child by sending him to another community to live with her extended family, where he experienced further trauma due to the pervasive impacts of intergenerational trauma.

A final consideration is Catlyn's comment, "If a person is suffering with ADHD or mental health issues or something like that, I personally believe that they should have access all the way across the board." This comment could be viewed as relating to debates about equality of opportunity versus outcome; however, based on my experience in the mental health field, I interpret it as a commentary on the underfunding of mental health services in general. Caitlyn had been talking about how difficult it is to find services for her non-Aboriginal clients compared to her Aboriginal clients, which is arguably a good example of the paucity of services in general.

In summary, challenges often arise in school, yet Aboriginal children are the ones expected to change, and Aboriginal caregivers must fight to get services for their children. These factors arguably are not consistent with principles of allyship and anti-oppressive practice which puts the burden on the oppressor, not the oppressed. Finally, mental health service in general are arguably not enough for most people in society, let alone our most vulnerable.

Vicarious Trauma

On top of the documented struggles that caregivers of children diagnosed with ADHD face, this study adds the recognition that caregivers in certain jobs, such as those working with vulnerable populations, may experience increased levels of distress. This is because they are confronted with the worst-case scenario for their children every day. We can understand this by looking at the concept of vicarious trauma. Vicarious trauma is a concept that was introduced by

McCann and Pearlman (1990) to describe the profound impact that working with people who have experienced trauma can have on professionals, specifically on their worldviews, identity, sense of meaning, and beliefs about self and others (Pearlman & Saakvitne, 1995). In Canada, it has been explored with family physicians (Woolhouse et al., 2012), lawyers (Leclerc et al., 2020), and forensic mental health professionals (Bradford & de Amorim Levin, 2020). It can create a sense of being disconnected from loved ones, make one view the world as being dangerous, decrease trust in others, and be associated with high levels of depression symptoms (Jankoski, 2010). One participant endorsed significant fear that her child would be victimized. While she tried to teach her to be cautious of strangers without making her think that every stranger was going to try to kidnap her, this participant endorsed that this was difficult to do because of her fear based on what she experiences at her place of employment. This arguably adds an important element to consider when supporting Aboriginal families with children diagnosed with ADHD.

A Spectrum of Etiologies

Based on my clinical experience and on the experiences of participants in this research, I argue that there is a spectrum of possible etiologies for the behaviors we associate with an ADHD diagnosis. On one end of the spectrum, there is ADHD that is largely biologically based. There may be a strong family history of ADHD and limited adverse childhood experiences. On the other end of the spectrum is ADHD that is largely based on environmental factors, such as intergenerational trauma, complex trauma, and other adverse childhood experiences. Indeed, in a study conducted in the United Kingdom, doctors described categorizing ADHD into “pure/true” and “pseudo” types to try to deal with the complexity of biological, psychological, and social factors (Kildea et al., 2011). The former has a neurological basis while the latter is rooted in

adverse childhood experiences. Two participants in this study exemplify each end of this proposed spectrum.

On one end, Alice's family has a strong history of ADHD, with she herself having a diagnosis of the disorder. Alice did not disclose any significant trauma for herself or her children, although she endorsed growing up with shame about being Aboriginal. This had become a strength for her as she had resolved that she would not pass that on to her children and was, as such, very connected to her cultural identity. Alice indicated that "the brain just fires differently for ADHD kids" and she reported improvements with medication.

On the other end, Brooklyn's upbringing was filled with complex trauma and she grew up in foster care. She struggled with alcohol abuse and her son was in turn abused and neglected. She described her son's ADHD diagnosis as being connected to his experience of complex trauma and adverse childhood events. She noted, "I think that the way his brain developed, having to fend for himself, it just developed differently," reflecting the literature on the effects of adverse childhood events and complex trauma on developing brains (Jackowski et al., 2009; Milani et al., 2017; Puetz et al., 2017; Schore, 2013). Brooklyn endorsed negative experiences with medicating her child.

This arguably has implications for treatment. If one child's ADHD is more biologically based, medications would be appropriate. If another's is based on environmental factors, medications may further marginalize the family and lead to further trauma. In these cases, caregivers may be left thinking that medications are like "residential school in a bottle," as was expressed by an Aboriginal mother in Manitoba (Oldani, 2009). This is arguably because Aboriginal children are expected to change to meet Western standards of behavior, instead of receiving the appropriate support they need to heal from the effects of colonialism.

As Baskin (2007) notes, how mental illnesses are defined and understood impact how they are approached and treated. Currently, it is likely that children who have experienced complex trauma are being inappropriately diagnosed with ADHD and prescribed medications and behavioral interventions rather than addressing their trauma. Evidence suggests that ADHD may be misdiagnosed among children and youth who have experienced trauma (Bith-Melander et al., in press; Szymanski et al., 2011), and family impairments not related to ADHD may be mistakenly associated with ADHD during assessment if care is not taken with symptom-specific wording (Vazquez et al., 2018). Kildea et al. (2011) found that the complexity of ADHD generated anxiety in doctors, which they then tried to deal with by categorizing patients into pure and pseudo groups. This categorization did not accurately describe practice-based situations, which generated further confusion and anxiety. This is why I have chosen to present possible etiologies of ADHD as existing on a spectrum, with biological, social, psychological, and spiritual factors influencing presentation and treatment variably. Mental health disorders assist in defining appropriate treatment approaches and it is possible that the options currently available do not adequately capture the experiences of Aboriginal families.

A Focus on Strengths

Every participant in this study discussed the strengths of their children and themselves. A strengths-based approach is based on identifying and amplifying the strengths that people have and values client participation (Payne, 2014). It has a long history in social work and is now considered foundational (Mendenhall & Carney, 2020). Indeed, a strengths perspective has been identified as being important in Indigenous suicide research (Dudgeon et al., 2020). Participants used words like “smart” and phrases like “beautiful little mind and “a psychologist’s brain that can analyze people and situations” for their children, and descriptors such as “advocating for that

kid and not stopping," "I've switched my ways of being," "I would do anything for her," and "I keep trying" for themselves.

A strengths perspective is largely absent in the current literature on caregivers' experiences, which focuses on burdens of care. I specifically included questions about strengths in my interview guide to be consistent with trauma-informed principles, which undoubtedly influenced this finding. It is clear that these conversations are largely not occurring in the literature on experiences of ADHD, likely due to the lens that researchers bring to the research. For example, Leitch et al. (2019) used a qualitative approach to "understand parents' lived experiences of stress, namely the identification of stressors" (p. 2). This lack of a strength perspective is arguably problematic. If research does not include strengths, it could potentially do harm by reinforcing lessons taught by trauma or miss key aspects of experience that can inform better approaches to treatment and support. Moreover, our current clinical approach to helping families with children diagnosed with ADHD focuses on remediating their deficits through behavioral and/or pharmaceutical intervention, rather than building on their strengths.

Summary

This chapter focused on discussing the findings in the context of existing research, as well as connecting it to topics of allyship and vicarious trauma of working parents. I then proposed that the experiences of families living with ADHD exist on a spectrum, highlighting the importance of understanding the possible etiology of ADHD for a particular child in order to effectively offer support. Finally, I included a discussion on strengths. The next chapter will conclude my thesis.

Chapter Six: Conclusion

ADHD is a controversial diagnosis that is debated in public and professional spheres. The experiences of Aboriginal caregivers have largely not been included in research on the topic. This is problematic considering the impacts of colonialism, the risk of trauma symptoms being misdiagnosed as ADHD, and the different paradigms of mental health and mental illness according to traditional Aboriginal worldviews. In this study, participants' experiences highlighted how the burden is placed on Aboriginal caregivers to fight for services for their children. This occurs in a system that is based on biomedical assumptions which may neglect other factors that influence children's behavior, such as intergenerational and complex trauma. When considering principles of allyship and anti-oppressive practice, ethical questions arise about how services are currently delivered. Moreover, caregivers may experience added stress from vicarious trauma. Finally, the etiology of ADHD may better be understood as existing on a spectrum including situations in which it may be more biologically based, and situations in which it may be rooted in experiences of intergenerational and complex trauma. Medications may be helpful in the former and harmful in the latter. It is therefore important to assess trauma experiences and adverse childhood experiences using a strengths perspective to determine the appropriate treatment approach. Without an understanding of the context of historic and ongoing colonialism and the impact of intergenerational trauma, Aboriginal families may be left wondering, as one participant put it when discussing trying to get support for her child, "why have I had to fight this hard?"

Limitations

There are several limitations to this study. First, participants all lived in Prince George off-reserve, and research suggests that physicians approach diagnosis and treatment differently

compared to those on-reserve (Oldani, 2009). Second, this study focused on ADHD. However, evidence suggests that other behavior disorders such as oppositional defiant disorder (ODD) are associated with a greater risk of child maltreatment than ADHD (Ford et al., 2000), and it has been found that there is an increase in prevalence rates for conduct disorder (CD) in mid-adolescence for Aboriginal youth, at a rate that is double what is found in general population studies (Whitbeck et al., 2008). This suggests that ODD and CD may be diagnostic labels that are even more problematic if misapplied. Further, every participant in this study mentioned anxiety as a concern for their children, one participant going so far as to saying that anxiety likely accounts for the ODD diagnosis that her child was given. Third, I did not include specific questions about trauma or adverse childhood experiences, either experienced by the children or the caregivers themselves. Fourth, participants were all from Prince George and so are not representative of experiences in other parts of Northern BC. Fifth, participants in this study all had at least some post-secondary education, and as such, are not representative of the broader population. Sixth, all participants in this study identified themselves as female. It is likely that people of different genders and sexual orientations may have different experiences. Finally, this study did not consider the type of ADHD diagnosed, which is problematic considering that research suggests that there are different risk factors for inattentive symptoms and hyperactive-impulsive symptoms (Freitag et al., 2012).

Implications for Policy and Practice

This research may have several implications for policy and practice. As already mentioned, how mental illnesses are defined and understood impact how they are approached and treated (Baskin, 2007). By gaining an understanding of how Aboriginal peoples experience

and understand ADHD, service providers can better meet their needs. Based on this research, caregivers suggested the following regarding how services are organized:

- have mental health professionals more readily available in schools to decrease the pressure on working parents;
- have more services available after hours;
- increase access to healthcare professionals to assist with diagnosis in order to facilitate early intervention;
- decrease waitlist times for psychological testing; and
- create a pamphlet or website for parents with information about ADHD and the assessment process, and make these available in daycares and doctors' offices.

Caregivers also had the following recommendations for service providers working with Aboriginal families with children diagnosed with ADHD:

- listen to what kids and parents have to say;
- provide options outside of medications;
- acknowledge the difficulties that parents face and the insights that they might have;
- be clear and concise with parents;
- do not use medical jargon;
- be willing to work with caregivers as part of a team;
- be educated about colonialism, intergenerational trauma, and the impacts of trauma;
- treat people with compassion; and
- understand that parents are also struggling.

Barriers should also be addressed in the system that make caregivers feel like they need to advocate and fight to get services for their children. Moreover, the findings and my own clinical

experience suggest that the quality of support received from schools varies by school. School District 57 might consider revaluating its trauma-informed policy in schools, finding ways to make administrators of different school more accountable to approaches being used within their schools, and prioritizing the ability for children and youth to make connections in school above academic performance. Finally, this research suggests that psychiatric labels may be being inappropriately applied to Aboriginal children, with significant consequences for them and their families, and that greater care should be taken in the diagnostic process. To emphasize this point, I will include a short story here. Alice was a participant in this research whose child had been diagnosed with ADHD and oppositional-defiant disorder (ODD). Alice indicated that while she agreed with the ADHD diagnosis, she did not agree with the diagnosis of ODD. She thought that the oppositional behavior could be better explained by anxiety. Indeed, Alice contacted me in the final stages of the research to give me an update. Her son had finally been assessed. His final diagnoses included generalized anxiety disorder, ADHD, and some learning disorders. ODD was no longer attached to him.

There are four considerations for future research. First, future research should include the experiences of those living on-reserve and off-reserve, and from other communities in Northern BC, as well as those with different socioeconomic status, genders, and sexual orientations; the experiences of caregivers with children diagnosed with behavioral disorders such as ODD and CD; the perspectives of service providers such as family physicians, pediatricians, psychiatrists, teachers, counsellors, and social workers; and the overlap of anxiety and behavioral disorders. Second, future research may benefit from including specific questions about trauma and adverse childhood experiences, exploring experiences regarding the sub-type of ADHD diagnosed, and considering the experiences of Aboriginal caregivers working in positions where they may

experience vicarious trauma. Third, future research could benefit from including a strengths perspective and trauma-informed principles. Fourth, future research should examine how decolonization can be applied to psychiatry and the process of treating mental health issues. Anishinaabe scholar Renee Linklater (2014) applies the concept of decolonization to trauma work with Indigenous peoples. She argues that a decolonizing approach emphasizes the importance of Indigenous worldviews, knowledge, and practice; and encourages a critical analysis of the use of psychiatry and psychiatric labels (Linklater, 2014). Finally, future research should explore options for service provision and policy that addresses the recommendations caregivers identified in this research, as well as engaging stakeholders to further the discussion. In particular, the following question should guide future research: How can anti-oppressive and allyship principles be integrated into service provision so that caregivers are not left feeling like they must fight for services for their children and families?

Reflections on My Learning

Cultural humility and reflexivity were important concepts in this research. Therefore, this section will focus on reflecting on myself and what I learned throughout the research process by considering a selection of the questions described in Chapter One and concluding with a final reflection on the process as a whole. The first question I will discuss here is: "What do I do on a day-to-day basis that might contribute to inequality?" An early entry in my research journal on this question talked about my assumption as someone without children that caregivers would have time to talk with me for 2 hours. I reflected on how this assumption contributed to inequality and oppression by not recognizing the burdens placed on caregivers in society. A quote from my journal reads as follows: "Just because I have all of this time to focus on my education doesn't mean that caregivers do. I just did what I hate in my clinical practice:

dismissing the burdens and barriers that caregivers face in light of checking off the boxes that institutions want."

Another example of reflection on this question came after a participant had expressed surprise after we completed her interview; she had expected it to be much more clinical and had cancelled and rescheduled three times because of this. In my journal, I reflected on the practices within research which make it less accessible. In particular, I critically considered my own assumptions about what research is. In my journal, I wrote the following: "My experience with Myriam at McGill shaped my view of research as a tool of participation and liberation. Academically, I know it has been used to oppress Indigenous people and that it is intimidating for most others besides. The consent forms, the research procedures…these obscure what is most important: the relationship." I further reflected how this is related to my tendency to hide behind institutional structures and procedures so as not to show vulnerability. But in the words of Brené Brown (2010), "staying vulnerable is a risk we have to take if we want to experience connection" (p. 53). It was a humbling moment for me to acknowledge that my own insecurities and lack of courage to be vulnerable could contribute to inequality by reinforcing a culture of disconnection.

The second question I will discuss here is: "What do I learn about myself through listening to clients different from me?" I learned the different ways that my privilege impacts my daily life and the lives of those I interact with. During this research, I was working full-time, trying to complete my thesis, and caring for my younger brother who has a chronic health condition and struggles with his mental health. There were also a lot of very difficult things going on at work which led me to struggle with vicarious trauma, including nightmares, shifts in world view, and mood alterations. However, I had family and friends who were able to support me, as well as benefits which allowed me to access counselling. This was in drastic contrast to

one of my participants, Brooklyn, who had said, “it was too much on my shoulders.” She did not have healthy family members she could turn to, nor did she have benefits she could use. She and her son were very much alone.

Finally, this research was incredibly validating and frustrating for me. I struggle ethically with medical model approaches to mental health issues for many of my clients, beyond those struggling with ADHD. In my clinical experience, it seems that psychiatric diagnoses are being applied inappropriately to many children and youth who have experienced and are experiencing trauma, and to have this reflected in the research was validating. At the same time, I was frustrated by the limitations in our system that leaves medical model approaches as the only option to keep children and youth alive. To explain, I work primarily with youth who struggle with anxiety, depression, and suicidality. I often think we have to resort to medications to stabilize a crisis because it is the only option given to us within the system. I think that the system is so strained that we are resorting to band aid solutions for problems that require much deeper work. Some of the greatest progress I have seen has been with the Intersect School Program, where we are able to provide wrap-around support that focuses on mental health and meeting attachment needs. Often, I get the sense that professionals and caregivers ask, “what is wrong with these kids that they are struggling so much?” Instead, we should be asking, “what is wrong with our way of doing things?”

Summary

This chapter concluded my thesis. It discussed the limitations of the study, as well as the implications for policy and practice. I also included a section on my learning, incorporating concepts of cultural humility and reflexivity.

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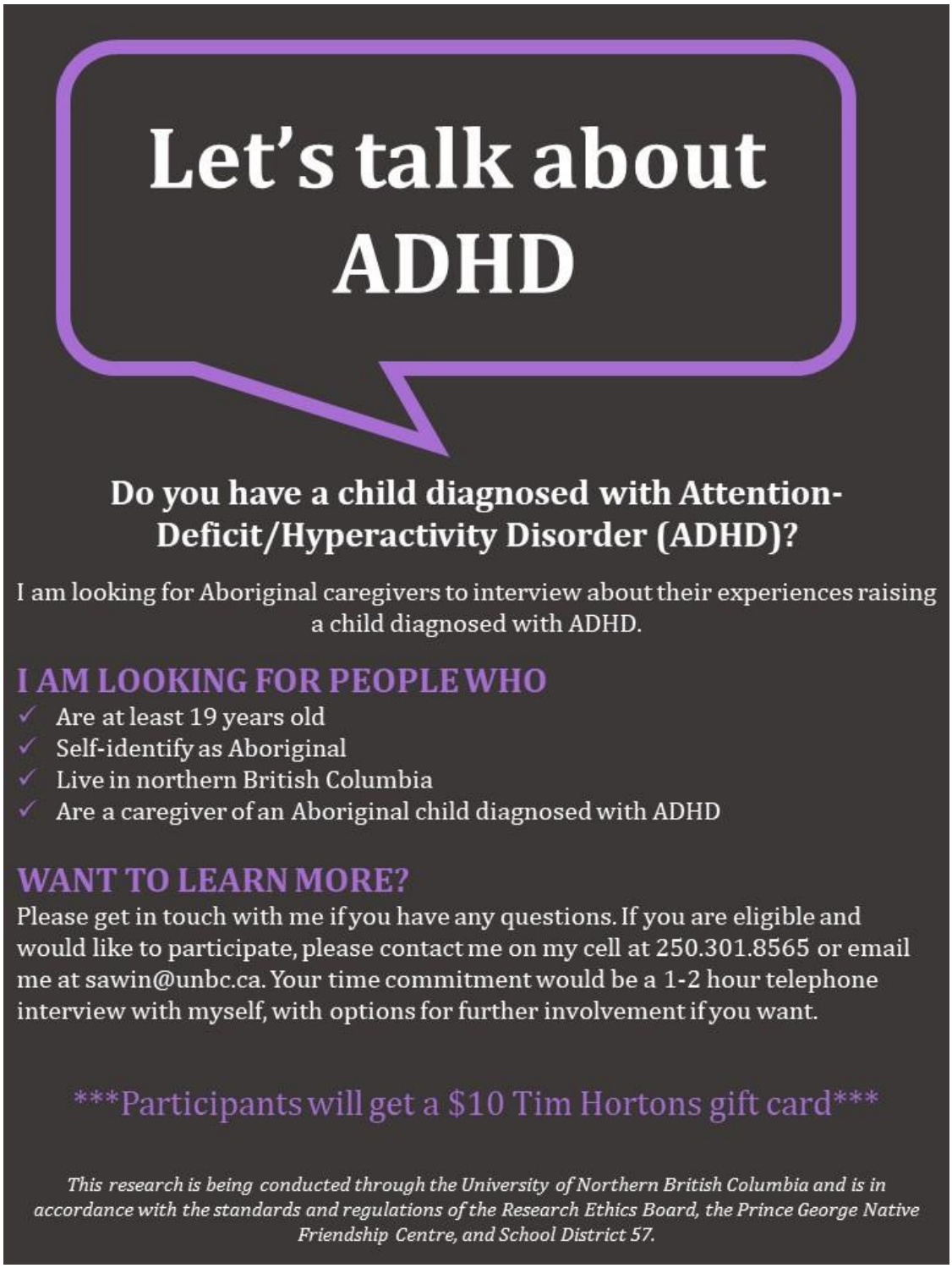
Appendix A: Recruitment Poster



Appendix B: Information Letter and Consent Form

Title: Decolonizing the debate: Experiences of Aboriginal caregivers who have children diagnosed with ADHD

Researcher: Nicole Sawin
University of Northern British Columbia
Prince George, BC
sawin@unbc.ca and (250) 301-8565

If you have any questions or need more information about this study after reading this information letter/consent form, please do not hesitate to contact me, Nicole, using either my email or phone number listed above.

Why am I doing this study?

My name is Nicole and I am a graduate student at the University of Northern British Columbia. I want to understand the experiences of Aboriginal adults who are the main caregivers of Aboriginal children diagnosed with ADHD in order to learn how to better help families.

What will happen during this study?

If you agree to participate in this study, we will schedule a time for an interview at your convenience. To facilitate social distancing to help limit the spread of COVID-19, only telephone interviews will be scheduled at this time. You are welcome to invite family members (above the age of 19) and Elders to attend the telephone interview. The interview will be 1-2 hours long and will be audio recorded if it is alright with you. If not, I will take handwritten notes during our interview. I will ask you about what it was like for you caring for an Aboriginal child diagnosed with ADHD. Basically, I want to hear your story!

After the interview is finished, I will type our conversation word-for-word. This is called an interview transcript. If you would like, I can provide you a copy via email so that you can see if there is anything you would like removed, added, or changed. If you would like something removed, added, or changed, you can let me know either via email or over the phone, depending on your preference. You will have 2 weeks to get back to me once you receive your transcript or I will assume that you are okay with me using the transcript as is.

Once I am finished writing the research results, you can participate in a second optional telephone interview if you want. The purpose of this second interview will be for you to provide me with feedback regarding the content of the findings and how I have written them up. This interview will also be 1-2 hours long. It will not be audio recorded. None of this is mandatory. You do not have to review your transcript or the research findings to participate in the research.

During this study, I will be consulting with an Aboriginal Advisory Committee every three months. They will not have access to your interview transcript. I may seek feedback from them on certain themes that come up not only in your interview, but also in others. This means that I may take a sentence or two of what you say, black out any identifying information (e.g., names of people or places), group it with things that other people say, and present it to the Aboriginal Advisory Committee to see if how I am coding (i.e., looking for common themes) makes sense. They will also be reading the research results and giving suggestions for how to present the results in the community. This will be helpful because I am a non-Aboriginal person so they can help me understand the results.

Is there any way that participating in this study could harm you?

Some of the questions I ask may seem sensitive or personal. You do not have to answer any question if you do not want to. If, at any point in the study, you feel uncomfortable or upset and wish to end your participation, please notify me immediately and your wishes will be respected.

Will being in this study help you in any way?

You may be helped in this study by being given the space to tell your story. In the future, other urban Aboriginal peoples in Prince George may benefit because your story may help service providers better support other families. Others in our society may also benefit because learning about your experiences can help us better understand what ADHD is like for different people.

How will your identity be protected?

Your identity will be kept confidential unless you disclose information that is beyond the limits of confidentiality (e.g., you indicate you intend to seriously harm yourself or others, you disclose information about a child or vulnerable adult who has been abused or neglected, or I am subpoenaed by a court of law). The audio recordings from the interviews will be saved on an encrypted USB flash drive and stored in a locked cabinet. All identifying information will be removed from interview transcripts and interview transcripts will be identified using an alpha-numeric code. These will be stored on my password protected computer and the files will be encrypted. You will not be identified by name in any reports of the completed study. The information gathered from this study will be kept for 5 years. After 5 years, paper records will be shredded and electronic files deleted.

Will you be paid for taking part in this research study?

In appreciation for your participation in this study, you will receive a $10 Tim Hortons eGift card. If you decide to withdraw from the study after completing an interview, you will still receive the gift card.

How will the study results be shared?

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books. It will be publicly available in the University of Northern British Columbia's library. You will be given the opportunity to have the graduate thesis mailed or emailed to you. A bound copy will be given to the Prince George Native Friendship Centre. The results will also be presented at community events, decided in consultation with the Prince George Native Friendship Center. Finally, a one-page handout will be created and distributed to physicians, mental health workers, and school staff.

Who can you contact if you have concerns or complaints about the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the UNBC Office of Research at 250-960-6735 or by e-mail at reb@unbc.ca.

Do you want to participate in this study?

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you can refuse to answer any questions that make you feel uncomfortable. You may also choose to pull out of the study up until the report completion without giving a reason and without any negative impact on your access to services as the Prince George Native Friendship Center. If you withdraw, any information you have shared with me will also be withdrawn and securely destroyed, unless you have consented to me keeping your information to include in the study.

CONSENT

I have read or been described the information presented in the information letter about the project:

YES NO

I have had the opportunity to ask questions about my involvement in this project and to receive additional details I requested:

YES NO

I understand that if I agree to participate in this project, I may withdraw from the project at any time up until the report completion, with no consequences of any kind:

YES NO

I agree to be audio recorded:

YES NO

I would like to read my interview transcript so I can see if there is anything I would like removed, added, or changed:

YES NO

I would like to be contacted to participate in a second interview to give feedback on the research findings:

YES NO

I would like copies of the following (please check all that apply):

- ☐ A hard copy of a one-page summary of key research findings
- ☐ An electronic copy of a one-page summary of key research findings
- ☐ A hard copy of the thesis
- ☐ An electronic copy of the thesis
- ☐ Any publications (e.g., journal articles, book chapters, etc.) – please circle one: mailed emailed

Please include your contact information below. You do not have to provide me with all of this information, but if you indicated that you would like anything emailed or mailed to you, please make sure to fill in the information I would need to do so.

Email: _____ Phone: _____

Mailing address: _____

_____

_____

Your signature below indicates that you consent to participate in this study. You will receive a copy of this consent form for your own records.

Signature: _____

Name of Participant (Printed): _____

Date: _____

Appendix C: Interview Guide

1. Can you tell me about how your child came to be diagnosed with ADHD?
2. What do you think about your child's ADHD diagnosis?
3. What do you think caused the behaviors that led to your child's ADHD diagnosis?
4. What challenges have you faced as a caregiver of a child diagnosed with ADHD?
5. What strengths do you have as a caregiver of a child diagnosed with ADHD?
6. What supports do you and your child have?
7. Can you tell me about your experience with your child's school?
8. Can you tell me about your experience with your child's doctor/pediatrician?
9. Some people agree with giving kids medications and some people don't. What do you think? How did you come to think that way?
10. In an ideal world, what supports do you think would be most helpful for Aboriginal children diagnosed with ADHD?
11. What advice would you like to give to other caregivers of Aboriginal children diagnosed with ADHD?
12. What advice would you like to give to service providers working with Aboriginal children diagnosed with ADHD and their families? (e.g., teachers, counselors, doctors, etc.)
13. What hopes do you have for your child?
14. Is there anything else that you would like to tell me about your experience raising a child diagnosed with ADHD?

Appendix D: Demographic Form

All questions on this form are optional. You do not need to answer if you do not want to.

Name: _____ **Date:** _____

Date of birth: _____ **Gender identity:** _____

Ethno-cultural identity: _____

Annual Income (check one):

_____ $0-$20,000
_____ $20,001-$40,000
_____ $40,001-$60,000
_____ $60,001-$80,000
_____ Over $80,000

Education level (check one):

_____ Did not complete high school
_____ High school diploma
_____ Trades
_____ High school equivalency
_____ Some college/university
_____ Bachelors
_____ Masters
_____ PhD
_____ Cultural education
_____ Other : _____

Current age of child diagnosed with ADHD: _____ **Total number of children:** _____

Age of child diagnosed when diagnosed with ADHD: _____

For researcher's use only

Alpha-numeric code: _____

Appendix E: Data Analysis

Figure E1

Constructing Themes

Table E1

Candidate Themes with Example Codes

Candidate theme	Example codes
Accessibility	• Lack of knowledge about resources • On waitlist for NHAN • Uphill battle
Indigenous identity	• Different microscope • Fear of being judge because Indigenous • Know where marks come from
Parent stress	• Questioned ourselves because unsolicited advice • Concerned about risk for victimization • Embarrassed in public
Advice to service providers	• Know that parents are also traumatized • After hours services • Need compassion from service providers

Figure E2

Thematic Map

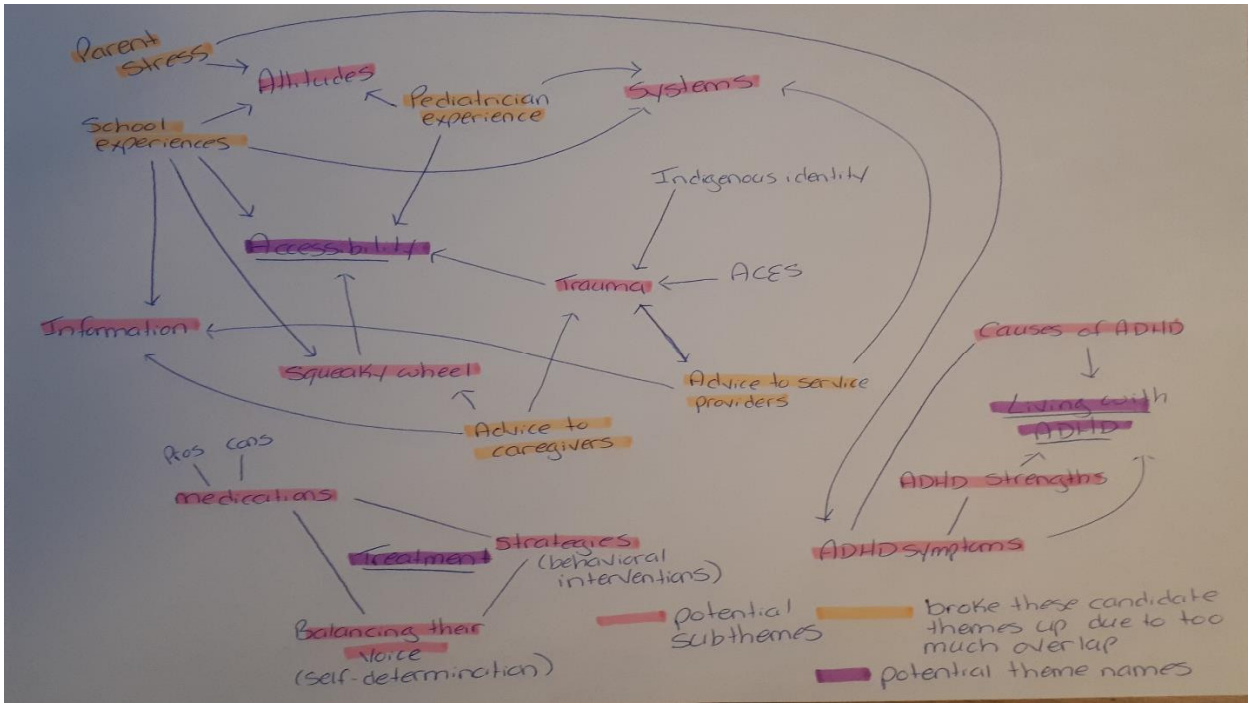


Figure E3

Theme Definition of "Trauma and Accessibility"

Participants identified several ways in which trauma impacted accessibility of services and supports. This included impacting parents' ability to learn from services, their ability to slow themselves down enough to access services, and limiting their access to family support. Participants also described "horrible" experiences coming out of schools not understanding their children's reactions due to complex trauma, and schools sending children home rather than supporting them. Participants described this causing further trauma by limiting parents' options of safe places to send their children and putting labels on their children. Participants also described how trauma increased accessibility by having them wanting it to be different for their children, whether it be by challenging the shame of their Indigenous identity or seeking healing for themselves and their children. Participants called on service providers to be educated about issues facing Aboriginal families, treat families with compassion, and understand that parents' may also be struggling with the effects of trauma.

Appendix F: Prince George Native Friendship Centre Letter of Support

Research Application

DELETE REPLY REPLY ALL FORWARD ...

Erin Anderlini <eanderlini@pgnfc.com>
Thu 2018-11-29 4:26 PM

Mark as unread

To: Nicole Sawin;

You forwarded this message on 2018-11-29 9:23 PM.

Action Items + Get more apps

Hi Nicole,
The PGNFC has reviewed your research application for: Decolonizing the Debate, and we support it with the changes that we discussed today. Please feel free to move forward and let us know should you need anything.
In friendship,

Erin Anderlini, MEd, RCC
Director of Health
Prince George Native Friendship Centre
1600 3rd Ave, Prince George, V2L 3G6
250-564-3568; 250-563-0924 fax, www.pgnfc.com

Appendix G: School District 57 Approval Letter

SCHOOL DISTRICT NO. 57(PRINCE GEORGE)

2100 Ferry Avenue, Prince George, B.C. V2N 4R5 Phone: (250) 561-6800 • Fax (250) 561-6801 www.sd57.bc.ca

Feb 19, 2020

Dear Nicole,

This letter is to confirm your request to use conduct your study in cooperation with School District No. 57 for the purpose of educational research. The school district recognizes the integral part that research plays in education. Your project ***Decolonizing the debate: Experiences of Aboriginal caregivers who have children diagnosed with ADHD***, is interesting and should provide useful information for your project and our district. This letter's purpose is to indicate that you have district approval to proceed with your research.

Upon completion of your project, the Board of Education requests a one-page summary of your findings.

Please forward this summary to the District Vice-Principal of Learning Innovations.

If you have any questions, please do not hesitate to call me. Good luck with your project.

Sincerely,

Trish Goodson
Vice-Principal, Curriculum & Innovation

cc: Deb Kaban, Director - Curriculum & Innovation

Appendix H: Research Ethics Board Approval Letters

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Nicole Sawin
CC: Glen Schmidt

From: Henry Harder, Chair
Research Ethics Board

Date: February 7, 2019

Re: **E2018.1211.111.00**
Decolonizing the debate: Experiences of Aboriginal caregivers who have children diagnosed with ADHD

Thank you for submitting revisions to the Research Ethics Board (REB) regarding the above-noted proposal. Your revisions have been approved.

We are pleased to issue approval for the above named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or consent form must be approved by the REB.

Good luck with your research.

Sincerely,

Dr. Henry Harder
Chair, Research Ethics Board

3333 University Way, Prince George, BC, V2N 4Z9, Telephone (250) 960-6735

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Nicole Sawin
CC: Glen Schmidt

From: Chelsea Pelletier, Vice-Chair
Research Ethics Board

Date: February 11, 2020

Re: **E2018.1211.111.01(a)**
Decolonizing the debate: Experiences of Aboriginal caregivers who have children diagnosed with ADHD

Thank you for submitting a request for renewal and amendments to the Research Ethics Board (REB) regarding the above-noted proposal. Your request has been approved.

We are pleased to issue renewal approval for the above named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of REB approval. Any further changes or amendments to the protocol or consent form must be approved by the REB.

Good luck with continuation of your research.

Sincerely,

Dr. Chelsea Pelletier
Vice-Chair, Research Ethics Board

3333 University Way, Prince George, BC, V2N 4Z9, Telephone (250) 960-6735

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Nicole Sawin
CC: Glen Schmidt

From: Henry Harder, Chair
Research Ethics Board

Date: February 25, 2020

Re: **E2018.1211.111.01(b)**
Decolonizing the debate: Experiences of Aboriginal caregivers who have children diagnosed with ADHD

Thank you for submitting amendments to the above-noted proposal to the Research Ethics Board (REB).

The amendments have been approved until the date as provided in the latest protocol approval for this project (i.e. February 10, 2021). Continuation beyond that date will require further review and renewal of REB approval. Any further changes or amendments to the protocol or consent form must be approved by the REB.

Good luck with your research.

Sincerely,

Dr. Henry Harder
Chair, Research Ethics Board

3333 University Way, Prince George, BC, V2N 4Z9, Telephone (250) 960-6735

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Nicole Sawin
CC: Glen Schmidt

From: Henry Harder, Chair
Research Ethics Board

Date: April 8, 2020

Re: **E2018.1211.111.01(c)**
Decolonizing the debate: Experiences of Aboriginal care givers who have children diagnosed with ADHD

Thank you for submitting amendments to the above-noted proposal to the Research Ethics Board (REB).

The amendments have been approved until the date as provided in the original protocol approval for this project (*i.e.* February 10, 2021). Continuation beyond that date will require further review and renewal of REB approval. Any further changes or amendments to the protocol or consent form must be approved by the REB.

During the COVID-19 pandemic, no *in-person* interactions with participants are permitted. Please refer to the Chair Bulletins found on the webpage at: https://www.unbc.ca/research/research-ethics-safety-human-participants for further details. If questions remain, please do not hesitate to contact Isobel Hartley, Research Ethics Officer at Isobel.hartley@unbc.ca or reb@unbc.ca.

Good luck with your research.

Sincerely,

Dr. Henry Harder
Chair, Research Ethics Board

3333 University Way, Prince George, BC, V2N 4Z9, Telephone (250) 960-6735